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## Accessing resources: The narratives of women working with a hearing loss

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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## Abstract and Keywords

This narrative study describes the stories of women who are experiencing a hearing loss while working. It seeks to understand why these women may or may not be accessing resources. A narrative approach was used in order to gain in-depth description of the experiences of the participants. Two one-on-one interviews were completed with each of the eight participants.

After analysis of the interviews, five themes emerged. These themes included degree of hearing loss and communication demands, childhood experiences, financial factors, knowledge and awareness of others, and workplace environments. Insights of this “invisible” disability as well as ways in which women understand and cope with their hearing loss are explained.

The results of this study will be used to facilitate future qualitative research in this area. They will be used to help change the ways in which individuals are managing a hearing loss while actively working.

**Keywords:** hearing loss; women; resources; working; workforce; narrative

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## Chapter 1

### 1 Introduction

#### 1.1 Prevalence of Hearing Loss

Approximately 19% of Canadians aged 20 to 79 years old (4.6 million people) in 2012/2013 “had hearing loss that affected their ability to hear normal speech” (Feder, Michaud, Ramage-Morin, McNamee, & Beauregard, 2015, p. 20). Hearing loss can either be congenital or it can be acquired during a person’s lifetime. Congenital hearing loss develops prior to birth or shortly after birth (World Health Organization [WHO], 2017). There can be a number of different causes of congenital hearing loss including, but are not limited to maternal drug use during pregnancy and low birth weight (WHO, 2017). An acquired hearing loss may have a number of causes including exposure to noise in the workplace (noise-induced hearing loss), infectious diseases such as meningitis, measles and mumps, chronic infections, or the aging process (Presbycusis) (WHO, 2017). Individuals with mild or moderate degrees of hearing loss may be able to communicate very effectively in low noise situations; however background noise can present a significant communication difficulty for an individual with hearing loss even with the use of hearing aids (Kochkin, 1993).

Although many of the effects of hearing loss can be minimized by the use of hearing aids, there remains a perceived stigma associated with hearing loss and the use of hearing aids (Johnson et al., 2005). The term stigma refers to “an attribute that is deeply discrediting” (Goffman, 1963, p. 3) that can lead to discrimination, stereotyping, separation from or rejection by others (Link & Phelan, 2001). The stigma related to hearing loss is associated with experiences of ageism, vanity and altered self-perceptions such as being abled or disabled, and intelligent or cognitively impaired (Wallhagen, 2009). Manchaiah et al. (2015) completed research that looked at the social representation of hearing aids in different countries and found that “hearing aids are still seen negatively by the general population, and this may to some degree explain why only a few people with hearing loss choose to acquire hearing aids even though they have been found to be beneficial” (p. 1612). In addition to stigma, self-stigma also exists and occurs when individuals with

stereotypic characteristics, such as hearing loss agree with the stereotypes that exist and recognize they may be devalued by others (Gagné, Jennings, & Southall, 2009; Major & O'Brien, 2005). There is a stigma attached to both individuals with hearing loss who have not accessed hearing assistive devices, as well as to individuals who use hearing assistive devices, such as hearing aids (Johnson et al., 2005). Hearing loss is not visible, but when a person with hearing loss makes use of hearing aids or other hearing assistive devices the presence of a hearing loss becomes apparent to others.

## 1.2 The Effects of Hearing Loss

The number of people who are working with a hearing loss continues to increase in part because of the increase in prevalence of hearing loss as persons age, and also due to changing retirement legislation that does not require persons to leave the work force at a prescribed age (Shaw, 2013). Working with a hearing loss poses a great number of challenges and difficulties. The impacts of these challenges can often be lessened when individuals seek the resources they need.

### 1.2.1 Communication

Communication is an integral part of life (Dalton et al., 2003) and is an important aspect of most people's careers. Some careers involve more communication than others. For all workers, communication with a hearing loss may become very difficult when individuals have not accessed the resources they need. Increased communication demands can lead to exhaustion and therefore possibly impact the safety of these workers (Jennings, Shaw, Hodgins, Kuchar, & Poost-Foroosh, 2010). Problems such as not being able to hear spoken warnings, bells, whistles, alerts or alarms can be detrimental to an individual's safety (Jennings et al., 2010). In addition, communication demands in the work place can also promote feelings of isolation at work (Jennings et al., 2010). This could be caused by the reduced communication with coworkers in hopes of preserving energy as well as the inability to participate in work related tasks due to the challenges created by the environment and by fellow employees or managers (Jennings et al., 2010).

### 1.2.2 Social Support and Social Inclusion

Social support and social inclusion are important predictors of a good quality of life (Adams, King, & King, 1996). When social interactions and social events become too exhausting and no longer appealing due to the effort required to communicate with a hearing loss, there are direct consequences that impact an individual's work life as well as their social life (Shaw, Jennings, Poost-Foroosh, Hodgins, & Kuchar, 2013). Social support and social inclusion often decline when individuals with hearing loss isolate themselves from coworkers, family and friends (Mick, Kawachi, & Lin, 2013). This decline in social interaction has a negative impact on the quality of life of individuals (Hallberg, Hallberg, & Kramer, 2008).

### 1.2.3 Financial Earnings and Job Promotions

Working with a hearing loss can also impact an individual's financial earnings and opportunities for promotions (Schroedel, Geyer, & McGee, 1996; Kochkin, 2007). When hearing loss is untreated, the negative impact on household income compared to that of individuals with hearing loss that have hearing aids is greater (Kochkin, 2007). In addition to the impact on financial earnings, Schroedel, et al. (1996) found that women with hearing loss were less likely to receive promotions than men working with a hearing loss. Individuals may conceal their hearing loss in order to avoid job loss and preserve advancement opportunities in the workplace (Hétu, 1996). Schroedel and Geyer (2001) found that the chances of promotions increased when requests for accommodations were provided to employers. Schroedel and Geyer (2001) stated that high quality communication with coworkers as well as a supportive relationship with a supervisor increased the opportunities for promotions.

The challenges described above are likely to become more significant within the next few years. There is an increased emphasis on positions that require good communication (Douglas, 2015). Although challenges will vary depending on the type of workplace, some common changes in communication trends have and are continuing to occur. The emergence of working within teams requires individuals to communicate more frequently and effectively with others than when the workplace was primarily focused on individual

work (Douglas, 2015). Additionally, technological advancements are leading to a virtual organization (Barner, 1996). The workforce uses less face-to-face communication and more telephone, and video communication (Barner, 1996). These changes have the potential to increase the challenges related to working with a hearing loss.

### 1.3 Benefits of Accessing Resources

Working with a hearing loss can become a greater challenge if the signs and symptoms of a hearing loss are ignored. It is important for individuals to recognize changes in hearing abilities and access the help that is required in a timely manner. There are many resources available today that can assist persons with most types of hearing loss and the resulting communication challenges. These resources are not limited to hearing aids and may include other hearing assistive devices such as amplified telephones, FM systems and visual alerting systems; attending focus group sessions; visiting an audiologist or physician; having open discussion with an employer, friend or family member; having an initial hearing test or subsequent hearing tests conducted; having a workplace assessment carried out by occupational therapists or ergonomists that can result in modifications to workspaces or job requirements, and; access to counselling to assist with coping with workplace demands (Shaw et al., 2013). Hearing aids, amplified telephone devices and FM systems have the ability to improve the signal-to-noise ratio for individuals with hearing loss, i.e. making it easier for the persons with hearing loss to hear what they want to or need to hear and reducing the interference of unwanted sources of sound (Thibodeau, 2010; Kepler, Terry & Sweetman, 1992). Accessing resources when working with a hearing loss can significantly improve an individual's quality of life, both at work and outside of the workplace. Being able to communicate and remain involved in activities and events with coworkers will allow individuals to remain socially connected. This social inclusion directly relates to an improved quality of life, especially for women (Adams et al., 1996; Danermark & Gellerstedt, 2004). The decreased chances of injury or illness due to proper safety measures will also improve overall quality of life (Jennings, et al., 2010). Individual finances are more likely to remain stable and possibly improve (Kochkin, 2007). Workers who use the available devices and resources to minimize the impacts of their hearing loss report they are more likely to remain competitive with other

workers and have an increased chance for promotion (Tye-Murray, Spry, & Mauzé, 2009).

Additionally, using hearing aids as an example, Arlinger (2003) reported that individuals with hearing loss who acquired hearing aids had better relationships at home and outside of home and overall were more self-confident.

## 1.4 Prevalence of Individuals Accessing Resources

Wallhagen (2009) describes that, although the number of individuals experiencing hearing loss continues to increase, the number of people accessing hearing aids and other resources remains low. According to the National Institute on Deafness and Other Communication Disorders (NIDCD, 2009) approximately 20% of individuals who could benefit from hearing aids actually use them. Wallhagen (2009) states that although “the functional and psychosocial importance of hearing would seem to provide a strong basis for a desire to correct or ameliorate any loss” (p. 66), few individuals are accessing resources that can help to improve the challenges associated with hearing loss. If resources are accessed and appropriately utilized, the opportunity to significantly improve the quality of life of individuals with a hearing loss will increase (Arlinger, 2003).

## 1.5 Potential Factors Impacting Individuals from Accessing Resources

As previously described, hearing loss is often considered a disability causing people to be perceived as old and less capable (Wallhagen, 2009). Reluctance to acknowledge hearing difficulties might indicate the need to avoid stigmatization and preserve a positive self-image (Héту, Riverin, Getty, Lalande, & St-Cyr, 1990). Stigma towards hearing loss and hearing assistive devices has been found to be a barrier to reaching acceptance of the hearing loss and also the acceptance and use of hearing assistive devices (Wänström et al., 2014). The stigma of hearing loss may play a role in whether or not an individual with hearing loss will accept their hearing loss and potentially access resources; however it is not clear if this is a primary reason for most people or if each individual has a variety of reasons relating to their experiences (Héту, 1996). In addition to stigma, maladaptive

coping mechanisms which include avoiding social situations and interactions with others are also a barrier that can influence the acceptance of a hearing loss and therefore the decisions to access resources (Wänström et al., 2014).

Adults pursue professional help for hearing loss approximately 10 years after they first notice their hearing challenges (Davis, Smith, Ferguson, Stephens, & Gianopoulos, 2007). Individuals with hearing loss often avoid recognition of their hearing loss and as a result they avoid receiving the help they require (Davis et al., 2007). Help seeking for hearing loss needs to take place much earlier to ensure the best possible outcomes for individuals. Individuals are more likely to seek help if they perceive their hearing loss as poor, their actual degree of hearing loss is moderate to severe, they are older in age, they consider there to be more benefits than barriers to hearing aids, and perceive their significant others as supportive (Meyer & Hickson, 2012).

In order to understand how and why people with hearing loss in the workplace access, or do not access, appropriate resources, the individual's experiences of working with a hearing loss must first be understood.

## 1.6 Gender Differences

The challenges pertaining to acceptance and stigmatization are significantly different depending on gender. When women experience hearing loss in the workplace, the impacts related to their quality of life are greater than those experienced by men (Hallberg et al., 2008).

Men and women have shown different priorities and indicators of quality of life. Magilvy (1985) reported that “the best predictors of quality of life in deaf and hearing-impaired older women are social hearing handicap, functional social support and perceived health” (p. 143). The perceptions of women relating to the way they feel about themselves, as well as the ways that they believe others perceive them has an impact on their health (Magilvy, 1985). Hallberg et al. (2008) found that women with noise-induced hearing loss had a much lower self-reported quality of life than men with this type of hearing loss. In addition to perceived quality of life, social support was significantly related to



positive health in women (Magilvy, 1985). Women who believed they had healthy social relationships were more likely to feel better about themselves and their health (Magilvy, 1985). However, even when positive relationships exist, many women will avoid social situations, in order to avoid communication challenges that may result in them being viewed as “abnormal” (Hallberg & Jansson, 1996).

Relating to the workforce, working-age individuals with hearing loss are at an increased risk for reduced quality of life, and women are at higher risk than men (Danermark & Gellerstedt, 2004). The job demands and the amount of control an individual has at work can impact the health and well-being of the worker (Danermark & Gellerstedt, 2004). Job demands describe the requirements of an individual’s work and what is expected of an individual when at work (Danermark & Gellerstedt, 2004). Job control is the amount of control an individual has over their workplace tasks (Danermark & Gellerstedt, 2004). High demand jobs where employees have low control are stressful and more likely to lead to increased health risks (Danermark & Gellerstedt, 2004). These types of high stress jobs are more prevalent in women, which directly relates to increased challenges for women working with a hearing loss (Danermark & Gellerstedt, 2004). Many women are also in an unfavourable position to control their work situation leading to further increased stress levels (Danermark & Gellerstedt, 2004). These combined high levels of stress relate to the fact that women who are working with a hearing loss have more physical and psychological difficulties such as neck and back pain, headaches, irritation, frustration and insomnia (Danermark & Gellerstedt, 2004; Gellerstedt & Danermark, 2009).

The number of individuals working with hearing loss continues to increase, however the number of individuals accessing resources such as hearing aids remains low (Wallhagen, 2009). The aim of this study is to better understand accessing resources for hearing loss through the stories of eight working women who have hearing loss.

## 1.7 About the Researcher

I originally became interested in the field of hearing and hearing science after experiencing a temporary hearing loss in my right ear. After frequent visits to an

audiologist, I began tailoring the final years of my undergraduate degree towards hearing and communication sciences. As a younger woman, trying to work and attend school, I experienced many difficulties relating to communication demands, stress, and depression. Although I did not require hearing assistive devices, my personal experiences relate to the subject of my research study and this helped me to connect, establish rapport, and to empathize with study participants.

I also have close friends and family members who are working while trying to manage their hearing losses.

Prior to beginning this study I assumed that the stigma attached to hearing loss was still present based on my experiences. I believed that hearing individuals did not understand the challenges that individuals with hearing loss experienced both at the workplace and outside of the workplace. I also assumed that disclosure to employers and the use of assistive devices and additional resources would be of benefit to individuals with hearing loss.

## Chapter 2

### 2 Methodology and Methods

#### 2.1 Purpose

The purpose of this study is to understand the stories of women with a hearing loss who are engaged in the workforce. It seeks to understand their experiences relating to accessing resources and why these women accessed or did not access resources. If women had accessed resources, information regarding what resources they accessed as well as their experiences with these resources is described. A resource for the purposes of this study refers to anything that provides assistance or information to an individual, both inside and outside of the workplace. It is important to understand reasons as to why some women may or may not have taken the initiative to access resources. Examples of resources may include using hearing assistive devices such as hearing aids, FM systems, amplified telephones and visual alerting systems; attending focus group sessions; visiting an audiologist or physician; having open discussion with an employer, friend or family member; and having an initial hearing test or subsequent hearing tests conducted. In order to help improve the lives of individuals working with a hearing loss, it is important to understand their stories and personal experiences in a way they choose to share them. Findings will be used to increase knowledge and awareness of the impacts of hearing loss on women who are working and to identify future implications. This study will begin to construct a knowledge base for further research that will help remove the stigma of hearing loss and in turn improve the quality of life of individuals living and working with a hearing loss.

#### 2.2 Methodology

This study used a narrative methodology. The narrative methodology was informed by a constructivist/interpretivist paradigm because the study sought to understand “the world of human experience” (Cohen & Manion, 1994, p.36). In this study, the researcher was seeking to understand *how* the participants described their experiences and *why* some women have accessed resources and *why* others have not. Jonassen (1991) states that

“constructivism is a function of *how* the individual creates meaning from his or her experiences. We all conceive of the external reality somewhat differently, based on our unique set of experiences with the world and our beliefs about them” (p.10). Relating to the interpretivist facet of the paradigm, Neuman (2000) described that interpretivist research seeks to understand and interpret the reasons, motives and meanings for individual’s actions and personal experiences.

The study produced a collection of personal stories which varied depending on the experiences of the participants. Narratives allow for individuals to open up and describe all aspects of their life that they wish to share. This allows for specific, personal and rich data to be disclosed.

The researcher’s roles for this study included conducting the interviews, analyzing and interpreting the data, writing the stories for each of the participants, reviewing the stories with each of the participants and writing the results into a dissertation. This study did not involve the use of persuasive questioning. The researcher, who was also the interviewer, played a secondary role while the narratives were being told. This allowed the researcher to capture the true stories and emotions of each individual as they chose to present them. The researcher and one co-investigator participated in the analyzing and interpreting of the data and reviewing and providing feedback on the stories. The researcher transcribed the initial participant interviews and had assistance from a Western University undergraduate and graduate student for the transcription of the remainder of the interviews. Approval to conduct this study was obtained from the Health Sciences Research Ethics Board at Western University.

## 2.3 Study Design

### 2.3.1 Recruitment

Participants were recruited through placement of information posters in the H.A. Leeper Speech and Hearing Clinic at Western University, the Translational Research Unit in the National Centre for Audiology, and public places. Information posters were also mailed out to women who were in the Translational Research Unit’s research database and had previously agreed to be contacted regarding participation in research projects.

Information posters asked those interested to contact the researcher by either email or telephone.

Women 18 years of age and older who were actively working or had recently worked (within the past 12 months) a minimum of 20 hours a week for pay (i.e., not as a volunteer) were eligible to participate in the study. Only women who were engaged in paid work were recruited because the possibility of being able to leave or change positions is often higher for volunteer positions than for paid positions (Freeman, 1997). Participants were required to have hearing loss in at least one ear that they believed was affecting their ability to communicate on a daily basis. Documentation of the hearing loss through provision of a copy of the most recent hearing test results (an audiogram) was required. The audiograms were either brought into the first interview or were released to the principal investigator from the participant's hearing healthcare professional upon the completion of an authorization form. If the participant did not have an audiogram from within the past 12 months, a 30-minute hearing test was completed at Western University at the first interview session. Participants were required to speak English fluently and agree to be recorded during the interviews. Women were not required to have accessed resources prior to or during this study. Women who contacted the researcher and scheduled an initial interview, all met the above requirements and no one was excluded during this study. One potential participant emailed the researcher expressing interest, however did not respond when she was asked for her availability.

Women who were not able or willing to come to Western University or did not have access to an audiogram were to be excluded from participation in this study, on the basis of the exclusion criteria. However, it was not necessary to exclude any potential participants. For those potential participants who did have access to an audiogram but were not able or willing to come to Western University for the interview, the interview could take place in their home. One participant had their interviews completed in their home.

Eight women participated in this study. Although there are no concrete numbers as to how many participants is sufficient for narrative research, any number of participants can

provide new and insightful information providing the research methods are appropriate (Adler & Adler, 2012).

### 2.3.2 Data Collection

This study included two one-on-one audio-video recorded interviews with each participant. During the study, all interactions between the participants and the researcher remained professional. This ensured that there were no conflicts of interest and that the data collection remained ethical. Interviews were controlled by the participants and evoked by the researcher. The interviews were held in the HearCare Audiologic Rehabilitation Laboratory within the National Centre of Audiology, Elborn College at Western University. This lab is a small-enclosed room, with audio-video recording equipment in place. It is a welcoming and secure environment that includes a round table, chairs and a small kitchen area where drinking water and tissues are available. If participants were not comfortable or were unable to get to Elborn College, the recorded interviews could take place in their own home. If participants did not agree to have the interviews audio-video recorded, audio recording alone was used. When the researcher was required to go to the home of a participant, the principal investigator was given information regarding when, where and for how long the researcher would be gone for. This helped to protect the safety of the researcher.

When the researcher was contacted by the participant, either by telephone, email or through text messaging a few screening questions (see Table 1) were asked to ensure that the person met the inclusion criteria for the study. Once the researcher confirmed that the participant met the inclusion criteria, an initial interview was scheduled. Directions to Western University or to the participant's home were exchanged during this time (information that was discussed is also included in Table 1). A reminder email or text message was sent to the participant two days before the scheduled interview. If participants had questions prior to the first interview, they were able to contact the researcher via email, text messaging or telephone.

**Table 2.1: Screening Questions and Information for Participants**

1. Name, year of birth and gender
-----------------------------------

2. Contact information (email or phone number)
3. Are you currently working a minimum of 20 hours a week or have you worked a minimum of 20 hours a week in the last 12 months?
4. Have you had a hearing test completed in the past year?
  - Yes
    - Do you have access to your audiogram (hard copy or ability to receive it from a healthcare provider)?
    - If no, are you willing to have another hearing test completed either by your hearing specialist or at Western University?
    - If no, kindly thank them for their time and explain to them that a recent audiogram is required in order to participate.
  - No
    - Are you able to come to Western University to have one completed on the day of the first interview?
    - If no, are you willing to have a hearing test completed on your own time and provide me with the results?
    - If no, kindly thank them for their time and explain to them that a recent audiogram is required in order to participate.
5. If participant requests an in-home interview:
  - Address information
  - Initial meeting time and location
  - Provide them with a brief study introduction
6. If participant agrees to come to Western University:
  - Initial meeting time and location
  - Provide information regarding location and directions
  - Provide Parking information – where they will meet to receive their parking permit
  - Provide them with a brief study introduction

The researcher then discussed the inclusion criteria and all details of the study, in order to ensure transparency. Written consent for the study was obtained prior to beginning the first interview. The consent regarding audio-video recording was revisited and signed by the participant at this time. The consent form was visually presented and verbally read to participants to confirm all information was heard correctly and was understood.

Participants were given time to read through the letter of information on their own and ask any questions regarding the details of the study. Participants kept a copy of the letter of information for their personal records. A copy of a recent audiogram (hearing test results) was collected from the participant. If the copy was not brought by the participant, an authorization to obtain records form was completed. If the participant did not bring a copy or did not complete an authorization form to obtain a copy, a hearing test was

completed prior to beginning the interview. Two participants had their hearing tested on site.

The researcher provided each participant with an explanation of what the term *resources* referred to for this study. Resources is a broad term that can be interpreted in a variety of ways. Loosely defining this term prior to data collection helped participants remain consistent with the research question when describing their stories. The researcher stated:

For my research, I consider a resource as being anything that provides information or assistance to you. Some examples include using hearing technology such as hearing aids or amplified telephones, participating in focus groups, attending group therapy, discussing your hearing loss with a physician, or audiologist, hearing tests, discussion with your employer about your hearing needs, and discussion with friends or family.

The researcher also explained the process of a narrative study. The researcher stated:

I will begin by giving you a starting question and from there you will lead the remainder of the interview. I am looking for you to explain your story with as many details as you feel are necessary. Since the interview is about you, you will be the leader of how you choose to answer the questions and tell your story. Prompt questions will be provided if they are necessary.

This clarified the difference between a question-and-answer interview and a narrative interview.

Before stating the opening question, the researcher asked each participant questions about their workplace environment, occupation title, daily communication demands and age. All questions were open ended, allowing participants to provide as much information as they wanted. The questions were asked so that the researcher could ensure the participant demographics related to the study were provided in order to have them accessible when analyzing the data (see Table 2).



**Table 2.2: Demographic Questions**

<ol style="list-style-type: none"> <li>1. What is your occupation / job title?</li> <li>2. On average how many hours do you work/ have you worked in the last twelve months each week?</li> <li>3. Description of career role- Explain what you are required to do on a daily basis at work.</li> <li>4. Communication- Do you feel your job requires much time spent talking with or listening to others as part of your job (on the phone, in person, on the computer, or at meetings)? If yes, please describe the activities.</li> <li>5. Listening- Does your job require you to listen for other sounds, such as the sound of equipment working properly, warning sounds, etc.? If yes, please describe.</li> </ol>
---

Once the background information was gathered, the initial narrative interview session began with a single, open-ended question that stated: “Please tell me about your story regarding working with a hearing loss and how this impacts you.”

A series of prompt questions were used when the participant reached a point in telling their story where they remained silent for a prolonged period (Chase, 2005). This was an opportunity for the participants to tell more of their story. These prompt questions were not used to interrupt the participant or change the subject at any time. If at any time throughout the study the participant did not wish to answer any of the questions asked or did not wish to expand any of their answers, they were not required to do so. Examples of prompt questions that were used can be found in Table 3.

**Table 2.3: Prompt Questions**

<ol style="list-style-type: none"> <li>1. Were there specific aspects of your life that you thought were impacted more than others?</li> <li>2. Please explain that in more detail.</li> <li>3. Please provide me an example of that.</li> </ol>
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Brief notes were taken by the researcher during the interview in order to remember points that needed to be revisited at a later time. This revisitation was either later in the first

interview or during the follow-up interview, depending on the participant's story. Important body language or visual cues that were observed were also noted by the researcher (Chase, 2005). The first interview was approximately 60 minutes in length. Before the participants left the first interview, the researcher explained that within approximately four to six weeks, they would be contacted to schedule a follow-up interview. The follow-up interview was not scheduled at the end of the first interview because transcription of the interview, preliminary analysis of their stories, including the creation of a written chronological narrative, needed to be completed before proceeding.

Following the first interview, the researcher summarized the findings separately for each participant into a single chronological narrative based on her understanding of their story. The process described by Ollerenshaw and Creswell (2002) as *restorying* was used. "Restorying is the process of gathering stories, analyzing them for key elements of the story (e.g., time, place, plot, and scene), and then rewriting the story to place it within a chronological sequence" (Ollerenshaw & Creswell, 2002). This narrative was then presented to the participant through email prior to the follow-up interview session. The newly developed narrative provided the participant with the opportunity to verify that the researcher had an accurate understanding of the first interview or to provide clarification for any inaccuracies. When the newly developed narrative was sent to participants, a second interview was scheduled. One participant did not have email access so the second interview was scheduled; the participant arrived early to the interview in order to read through the narrative. A reminder email was sent to participants two days before the scheduled follow-up interview.

The second interview focused on points of reflection and reflexivity from the researcher and the participants. Reflexivity is a form of personal reflection and is an important characteristic of both a constructivist/interpretivist viewpoint and a narrative methodology as it allows the possibility of reaching deeper, more descriptive details (Smythe & Murray, 2000). Reflection and reflexivity occurred following the first interview. The researcher read through the transcripts and listened to the recordings multiple times. The researcher wrote down any thoughts or questions that she had and brought them forward in the second interview. The researcher also continued reflecting

on the stories of the participant's when she was writing the chronological narratives. Lastly, the researcher had open discussion with the co-investigator following the interviews to summarize each participant's story. Participants also had the opportunity for reflection and reflexivity as they thought about their own story and had time to think about any details or information that they may have missed. They were also given time to read the narrative prior to the second interview. This allowed additional time for the participants to think about their stories as a whole and reflect on what was discussed. The second interview continued to expand on previous experiences. Examples of the types of questions that were asked in the follow-up interview are listed in Table 4. In addition to the participant having a written copy of the newly developed narrative, the researcher retold the main points of the first interview to the participant to ensure the information was correctly understood. This interview session was also used to address any questions or comments from both the researcher and the participant after having time to think about the first interview and read through the narrative that was developed by the researcher. The second interviews were again audio-video recorded or audio recorded based on the participant's consent. These interviews were approximately 30 minutes in length. The follow-up interviews were transcribed and any changes or new information that was discussed in the follow-up interview was revised in the narrative.

**Table 2.4: Follow-up Interview Questions**

<ol style="list-style-type: none"> <li>1. Is there any information that you forgot to include or wish to expand on from our first meeting?</li> <li>2. When you discussed _____, what did you mean by that?</li> <li>3. Please expand further on _____.</li> <li>4. When you discussed _____, is this what you meant by that?</li> <li>5. I understand that _____. Is this correct?</li> </ol>
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Participation in this study had no known risk of harm, but the sharing of stories had the potential to result in discomfort. Similar to other health conditions, when an individual is describing their past experiences and reliving how life was before their condition, it may be very hard for some people to express. A list of external resources including

information on how to contact the College of Audiologists and Speech- Language Pathologists of Ontario to get a list of local audiologists, Courses for Adults Hearing Loss at Western University, the Canadian Hearing Society, and the London and District Distress Centre was given to each participant.

### 2.3.3 Data Analysis

Data analysis followed Creswell's (2007) guidelines and began during the data collection phase. Data analysis and data collection were ongoing and intertwined throughout the study (Creswell, 2007). The approach that was used includes the following five steps:

- Create and organize files for data
- Read through text, make margin notes, form initial codes
- Describe the story or objective set of experiences and place it in a chronology
- Identify stories, locate epiphanies, identify contextual materials
- Interpret the larger meaning of the story
- Present narration focusing on processes, theories, and unique and general features of the life (Creswell, 2007, p.156-157).

Following the completion of each interview, all recordings were transcribed verbatim and uploaded to RQDA (a qualitative data analysis software). The transcriber made written note of any body movements, gestures, facial expressions or other non-verbal information from the participant and the researcher. The transcriber also uploaded the researcher's notes that were taken during the interview into RQDA. No names were used to identify participants: participants were assigned a unique participant number that was used in the filename of each interview and the same number was used to identify the participant within the transcript. The transcriber numerically labelled each line of the transcript in chronological order for easy reference. The researcher read through the transcriptions and listened to the interviews to ensure accuracy and to understand the story as a whole. The researcher's notes as well as the notes created through the transcription process were compared.

Each interview and narrative was coded following the completion of the interview session by the researcher. One co-investigator also coded two of the narratives after the interviews were completed. As the interviews were listened to multiple times by the researcher and the coding was completed by the researcher and the co-investigator,

important themes for each participant were identified. Common themes between participants were then determined. The participant themes and study themes were developed by comparing multiple codes across participants in order to create a newer, more condensed set of codes. Once the long list of codes became manageable, multiple flow charts and rough notes were created to form links between various points. These condensed codes and links between codes lead to the formation of the five study themes. The researcher and co-investigator compared the themes that were identified. If discrepancies existed, the team members discussed their findings as well as their reasoning's and compared them to the original data. Together, they decided on the most accurate coding option. Once a single list of codes and themes had been developed, the original interview data was reviewed once again to ensure accuracy. Findings that did not appropriately fit into themes were described separately. Refer to Figure 1 for an overview of the study methods.

The results section of this study includes the voices of participants, the reflexivity of the researcher, and a description and interpretation of the problem. The discussion section of this document builds upon the previous literature, and presents an opportunity for further research (Creswell, 2007).

#### 2.3.4 Ethical Considerations

When unpacking past experiences with individuals, it is possible to hear information that may result in an ethical dilemma that was not expected. Although the researcher did not anticipate hearing stories outside of those relating to the participant's hearing loss, narrative interviews often describe more than is expected (Smythe & Murray, 2000). The researcher was aware of ethical and legal guidelines in case the participant did disclose information that required access to external resources, such as crisis counselling. The confidentiality of the participant was respected. However, if other personnel or resources were legally required, this became the first priority. If participants requested to have information removed from the video and/or audiotapes, this information was removed. Some of the participants used the names of co-workers or employers during their interviews. This information was removed from the analysis.



**Figure 2.1: Methods**

## 2.4 Quality Considerations of Methodology

The researcher used Tracy's (2010) "Eight 'Big-Tent' Criteria for Excellent Qualitative Research" to examine the quality of this study. These criteria include worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence (Tracy, 2010).



## Chapter 3

### 3 Results

This section will provide a brief description of the participants, based on their self-report and present the results of the thematic analysis. Participant codes are used to identify each participant to protect their anonymity.

#### 3.1 Participants

Eight women between the ages of 20 and 60 years participated in this study. All completed the study in its entirety. Of the eight participants, seven agreed to audio-video recorded interviews that were completed in a research lab at Western University and one participant requested an in-home interview with only audio recording. This participant lived outside of the city of London and could not come to Western University. She was also not comfortable speaking when she knew she was being videotaped. During this home interview, the researcher made written notes about the participant's actions, hand gestures and facial expressions if they appeared to add meaning to what the participant was communicating verbally. The demographics for the participants are shown in Table 5.

**Table 3.1: Participant Demographics**

Participant Number	Age	Type of Employment	Degree of Hearing Loss (R/L)	Hearing Aids?(Y/N, Age when prescribed)	Other Resources? (Y/N, Describe)
AM001	50	Receptionist	R- Profound L- Severe- profound	Y- 42	Y-hearing assistive technologies, workplace accommodations, facilitative communication strategies, and aural rehabilitation
AM002	56	Administrator	R- Profound L- Profound	Y- 44	Y- hearing assistive technologies and workplace accommodations
AM004	60	Registration Personnel	R- Profound L- Profound	Y- 6	Y- hearing assistive technologies, workplace accommodations, and facilitative communication strategies
AM005	56	Manager	R- Moderate L- Profound	Y- 7	Y- facilitative communication strategies
AM006	56	Educator	R-Mild- moderate L-Mild- moderate	N	No
AM007	57	Sales Associate/ Cashier	R-Mild L-Mild	Y- 51	Y- requested, but did not receive workplace accommodations
AM008	20	Transportation Assistant/ Student	R-Mild- moderate L- Moderate	Y- 7	Y- tried other hearing assistive technologies, but not currently using them
AM009	59	Educator	R- Moderate -severe L-Mild- moderate	Y- 53	Y- hearing assistive technologies, workplace accommodations, and aural rehabilitation

Participant AM001 was a 50 year old receptionist. She was the first point of contact for the department. She reported that she worked very long days and had high communication demands. She was required to attend meetings, speak on the phone and speak in person with coworkers and patients. She experienced a rapid decline in her hearing loss, and was a cochlear implant candidate. After noticing she was missing a lot of things that were being said by others, she purchased hearing aids for the first time when she was 42 years old. In addition to her hearing aids, she used a microphone that connected wirelessly to her hearing aids. When she placed it close to the person she wanted to hear, it helped her to better understand the talker in a noisy environment. In the past she attended two aural rehabilitation group programs with other individuals who had hearing loss. She also used closed-captioning on the TV at home, phone amplifiers both at home and at work, and a visual alert for the doorbell at home. She requested and had a workplace assessment completed for more specific accommodations that addressed her hearing challenges at work. The workplace accommodation assessment was completed by the employee health nurse, the participant, the participant's manager and a consultant from a not-for-profit organization that provides individuals with hearing loss a variety of services and information, helping them work through their challenges related to their hearing loss. After the assessment was completed, it was agreed that meetings would have to be orchestrated in a way that was helpful for the participant. Small changes such as raising a hand before speaking, making eye contact if possible and ensuring there was only one speaker at a time were all recommended. The participant reported that some employees would forget to follow these instructions; however they would be understanding and accommodating when a friendly reminder was given. Other recommendations that were discussed, but not implemented, included carpeted floors, typed notes that could be sent to the participant following one-on-one meetings and the exemption from taking meeting minutes.

Participant AM002 was 56 years old and worked in an administrative role for a large company. She had many career changes within the last few years within the same company. Her most recent role was solely based on in-person communication. Her daughter asked her to go for a hearing test after recognizing that her mother was not

hearing very well. She first purchased hearing aids when she was 44 years old. She was a cochlear implant candidate due to her rapid decline in hearing loss. She tried using resources such as telephone amplifiers and FM systems, but reported that she did not have any success with any of these hearing assistive technologies. She accessed a workplace assessment and workplace accommodations. Accommodations included informational seminars and newsletters for other employees to help educate them on how to communicate with someone working with a hearing loss; modifications to the requirements of her job; an individual workspace with the installation of sound absorbing materials, and the ability to work from home once a week. The only accommodation that she reported to be helpful was working from home one day a week because this helped to reduce the exhaustion that she would experience when working at the office.

Participant AM004 was 60 years old and worked for a service company doing registration. Her role required constant in-person communication all day long. AM004 was first fit with hearing aids when she was six years old; however she reported that she did not wear them throughout her school years because of discomfort and the impact she reported that wearing them had on her self-esteem. She reported that the onset of her hearing loss was related to the use of antibiotics and her hearing declined throughout her lifetime, until one day, when she was 48 years old, she woke up with a sudden significant loss in her hearing. AM004 used a notification light in her office at work to inform her if her clients had arrived, if the fire alarm was going off or if she was required to go to the front desk for any other reason. She also worked in an enclosed, quiet office space, no longer used the telephone, and used closed-captioning when watching TV at home. She had also become accustomed to wearing her hearing aids on a daily basis.

Participant AM005 was 56 years old and worked as a manager. She worked from home and communicated mainly through email. She had occasional work meetings in office environments and sometimes attended large conferences. She reported communication challenges in these group settings. AM005 received her first pair of hearing aids at the age of seven. She reported that she did not wear them while in school because they were too much work and she was embarrassed to be seen wearing them. AM005 reported that she plans ahead to find appropriate seating in meetings in order to better see and hear the

speaker, but did not use any other resources in these situations. She had not spoken to her coworkers or employer about her hearing loss because she still often felt embarrassed.

Participant AM006 was 56 years old and worked very long days as an educator. She was required to communicate on a daily basis with students as well as coworkers. She was required to attend and facilitate meetings, teach large classes, and meet with students individually. AM006 had recently noticed herself asking people to repeat themselves more often. She went for a hearing test, spoke to family and friends and participated in this study, but did not access hearing aids or any other resources. AM006 did not feel ready for hearing aids and did not want the trouble of having to wear them every day.

Participant AM007 was 57 years old and stopped working approximately three months before participating in this study. Prior to this, she was a sales associate and cashier at a large business. She reported that in this job she needed to listen to customers and coworkers as well as use the telephone. AM007 first purchased hearing aids when she was 51 years old. She had initially gone for a hearing test two years prior to this because she was having difficulty hearing people in large groups. AM007 reported that she was mentally and emotionally ready to receive hearing aids directly after her hearing test results, although she needed some time to prepare financially for the purchase of hearing aids. Before she stopped working, AM007 approached her manager about workplace accommodations. She did not receive any support or information. She had not accessed any other resources at this time, but was open to trying and learning more about other available resources.

Participant AM008 was 20 years old and was a full-time student. She was working as a transportation assistant full-time during the study as part of her school placement. While working she was required to complete both group field work and individual office work. AM008 was prescribed with hearing aids when she was seven years old. Her family had a history of hearing loss and she had four siblings who also had hearing loss. She reported that she did not wear her hearing aids very often when she was younger and still did not wear them on a daily basis as an adult. She described her hearing aids as an inconvenience and she reported she was able to manage most situations without them.

AM008 had tried many resources such as FM systems, phone amplifiers, and a microphone that connected wirelessly to her hearing aids, but she reported that she did not receive any benefit from using them. She reported that they were too much of a bother and that they were not beneficial. She did not use any other resources, aside from occasionally wearing her hearing aids.

Participant AM009 was 59 years old and was an educator. She found it very exhausting having to communicate with the students in her classroom everyday as well as with her coworkers. AM009 first purchased hearing aids when she was 53 years old. She also had a workplace assessment completed in which she had a few changes made to her workspace. These changes included tennis balls placed on furniture legs, an area rug put into the room, sound baffling attached to the walls and a visual alarm installed that alerted her when the fire alarms were going off. There were also many recommendations that were not implemented, including a personal alert system for the school bells; texted versions of the morning announcements; a noisy music room being relocated away from her classroom; and children from other classes being asked to not complete group work in the pods outside of her door. She used a Bluetooth headset for her phone and closed-captioning on her television at home. She had attended two aural rehabilitation groups that she reported helped her immensely by allowing her to gain support from others who were experiencing similar challenges. Aside from the accommodations that were not implemented, she had success with the resources she had accessed, although she was still struggling with communication, exhaustion and frustration on a day-to-day basis.

### 3.2 Information Obtained through Email

After completing the interviews with each participant, participants consented that email contact may be used by both the researcher and the participants if any further questions or thoughts arose. One participant did not have email accessibility but was able to use text messaging as an alternative. During the analysis period, two participants decided on their own to send an email to the researcher explaining an event that had taken place since the last interview and to expand on their answer to a specific question posed by the researcher during the last interview. Any additional information that was provided in the

emails or text messages was incorporated into the stories of the participants, the analysis, and the final write-up.

### 3.3 Themes

After analyzing the interviews and stories, five key themes describing accessing resources emerged. These themes are: degree of hearing loss and communication demands, childhood experiences, financial factors, knowledge and awareness of others, and workplace environments. These themes are described below and representative quotes from the participants are used to illustrate each theme.

#### 3.3.1 Degree of Hearing Loss and Communication Demands

All participants had unique hearing losses. The degree of the hearing loss and how quickly the hearing loss progressed may have influenced the decisions of individuals to access resources. For one participant, she explained that the decline in her hearing led her to access multiple resources.

Uh, from there, we determined that, yes I need hearing aids...I had a gradual hearing loss. It was mild, then it went to moderate, to severe to profound. So now I believe I'm at—well my right ear is profound and the left ear is, I believe, severe to profound. Um, so [laughs] I don't know. I've been through many different hearing, uh, hearing aids to get stronger, be able to get some benefit from it.  
(Participant AM001)

Participant AM001 discussed that the more her hearing declined, the more resources she accessed. There were times when the hearing aids she had were still of benefit to her, however she required a change in the prescription and therefore took the initiative to make this change.

Sudden changes that individuals were not prepared for presented increased challenges for participants. These increased challenges influenced the participant's decisions to access resources based on their communication demands. Participant AM009 reported:

...and then about uhhh, three years ago, I woke up one day and had lost significant hearing in this ear [points to ear]. So, it got worse from there. So, umm, it became increasingly difficult for me to manage the class, to listen, to hear, umm to hear the fire alarm. The school I'm at now is a fairly new one...and

it has umm very weird bells. It is not a normal school bell, they're like a high-pitched squeal. And, I can't hear it. And, the fire alarm, interestingly enough, I don't know why, I don't know if this is standard, would ring outside my classroom...And I wasn't hearing the fire alarms...So, I thought, okay well this isn't good...I tried to get the board to do something and they wouldn't do anything.

One participant expressed that the degree of her hearing loss was manageable and therefore she decided not to purchase a hearing aid.

So yeah, it's not something that I totally disregarded, but I think, I just... while I can still be free of it for a while [laughs quietly]. And I don't think that they're as maintenance-free today as, of course, I would want them to be. No! They're not perfect. So I don't have a hearing aid. Now my neighbor has a hearing aid and, uh, [sighs] oh yes, oh, you know what, you can hear the light switches going on and off. And I'm thinking, well I can still hear that. (Participant AM006)

Participants also reported the difficulty of not having employers or other communication partners understand that the degree of hearing will be different for every individual. Hearing loss is not an all or nothing situation. Participant AM002 reported her difficulties when trying to explain that her hearing loss is different from that of other employees.

We were all put in the same pot. So, if [another employee with hearing loss] could hear the fire alarm, well you know, I could hear it. Well, I don't hear fire alarms. So, they didn't have a clue that my loss was here and [another employee's] loss was here, or, you know another [employee].

### 3.3.2 Childhood Experiences

Some of the participants experienced hearing loss at young ages. Growing up with a hearing loss resulted in a variety of negative experiences and outcomes described by these individuals. All participants described incidents of bullying and stigmatization, which influenced their choices to not use their hearing aids and assistive devices. One participant describes her experience by stating, "And, I was a child. People would tease me and torment me 'cause kids are mean. So I wouldn't wear it" (Participant AM004).

For similar reasons, participant AM005 didn't wear her hearing aids through childhood or when attending university. When she entered the workforce she began wearing them.



So I didn't—I think I was in—being in denial. And just being a kid, I didn't want to wear them. So, hopefully they've improved the aids for children because it was, uh—and then, in my teen years, of course, I didn't want to, you know, you wearing a hearing aid. So I really did feel it was a handicap. Like I felt embarrassed. You don't wanna be different. But—and even in university, I didn't have a hearing aid on. So I sat in the front of the class, like, you know, that accommodation thing. And, um, you know, just asked people to repeat things, type of thing. (Participant AM005)

In addition to having challenges with bullying and hearing aid use, the unwillingness of teachers to use the student's hearing assistive technology as well as the lack of knowledge on how to use this type of resource was reported. For example, one participant (AM008) said “So, uhh just like kinda certain experiences like teachers not knowing what to do or equipment not working would turn me off from using anything other than just a hearing aid”. Additionally, she reported “Then you're kinda like well, I have this resource, but I can't utilize it because the teacher's not going to”. This participant reported that she avoided using her hearing assistive devices at school because of the reactions from her teachers.

Incidents involving being teased by others were also reported. Children, who did not have hearing loss, did not have knowledge of the reasons for and benefits of hearing aid use, teased other children for using these devices. Participant AM004 describes her experience.

Umm I would've been probably six, I think when I got my first hearing aid, but I did not wanna wear it. They put it in the ear that had no hearing, so it didn't really help, and umm, kids are mean. I got picked on and teased and I don't remember doing this, but my dad said I would come home, take out my hearing aid, put it on the TV, turn the TV on and watch TV, so. And I don't know how expensive hearing aids were then, but I know it was a hardship for my parents, so at these appointments there was no OHIP (Ontario Health Insurance Plan). Umm, so my father just took it back, so I don't even know how long I had it.

For another participant, to try and avoid being teased, different types of hearing aids and devices were explored, however the participant still did not use the devices.

So I wore those up until- I would say a year or two. And the reason uhh, was because it was something new that had come out when I first started wearing them like about grade three or four, and then the school was worried about the class and also if I were to get teased by it. (Participant AM008)

The same participant expressed her habit of not wearing her hearing aids growing up and how this made it harder for her as an adult to remember to wear them.

Uhh, unlike my siblings who, after like we were diagnosed with hearing loss, they knew what to look for in the other ones, so, they got theirs as soon as they were born, like got it tested and everything. So, as soon as they wake up, they put their hearing aids on, they have like a whole routine and everything, whereas I'll wake up, get busy...then I'll get to work and then I realize like I forgot to put them on and like it's usually when I'm starting to talk to somebody that I notice it because I start missing things that they say. So, that's probably my biggest disadvantage that I do against myself is not wearing the resources that I have and using them. (Participant AM008)

A positive aspect that was described was that growing up with a hearing loss allowed the individual to make career choices as an adult based on their knowledge of their personal strengths and weaknesses. Participant AM008 stated, "And, all the jobs I've gotten, I've taken into account my hearing loss, whether or not it would affect me...Uhh, so that's always been something that I've kinda thought about before doing a job".

### 3.3.3 Financial Factors

Financial factors were described as an important factor for some individuals when deciding whether to access resources. The high cost of hearing aids was identified as a barrier by participants. One participant refused to get hearing aids after being told she needed them because of the expense.

...the cost factor—although I have insurance, it's only going to pay 85% of it and at \$6000, that's quite a bit of money. And I have two kids, like you, they're in school, and I wanna help them as much as I can. (Participant AM006)

Another participant reported that she saved for multiple years in order to get hearing aids because of the large upfront payment that was required. "I just thought well, maybe I should get my hearing tested but I didn't. Well, I did but then I didn't have the money to get the hearing aids" (Participant AM007).

This participant also reported that it took her two years after acquiring her hearing loss to save enough money to purchase hearing aids because she could not afford hearing aids when they were initially prescribed.

Once participants received their first pair of hearing aids, some could not afford to update them, resulting in the use of less effective technology than what was currently available.

Participant AM004 described her experience using older technology.

I know there's technology available. I'm wearing a really old hearing aid, because I have really crappy benefits and I can't afford a new one. I do need a new hearing aid, I just don't have the money for it.

This participant described further the difficulties that she faced when using older technology. She explained that she was required to manage with the older technology because she could not afford to buy new devices.

Financial factors were also described to play a role in when participants were able to receive hearing assistive devices such as hearing aids. One participant described having to make hurried decisions because of an unexpected job change. This participant needed her work benefits to help pay for the hearing aids. She reported not being able to try different options or explore different possibilities in order to find devices that suited her best because of time constraints.

Umm, so I went to work, and I said I need hearing aids, umm then they told me, my job was redundant, so I was umm, management at the time, and management had coverage for hearing aids, and then they said you are now going back to the Union, and the Union doesn't have coverage for hearing aids. So basically, I had two weeks. (Participant AM002)

After trying to work with her employer and agree on a suitable solution, the employer did not provide any additional support and she had two weeks to obtain a hearing aid with her employee benefit plans.

One participant misplaced her hearing aids and described not having them replaced because they were too expensive. This participant described feeling nervous to tell her parents that she lost her hearing aid because her parents provide her with financial support for her devices. Participant AM008 stated, "Yes, they do [help me]. I would prefer to wear two if I - just they are expensive. I get nervous admitting that like I lost them- to my parents". The same participant also reported not scheduling regular hearing health care visits due to the high cost and perceived lack of benefit. "Umm, I personally

find it a nuisance to always be going in and it's expensive to be paying for these check-ups all the time when I haven't had any issues with the hearing aids" (Participant AM008).

The high cost and financial burden of audiologic services and hearing assistive technologies prevented some participants from accessing these resources.

### 3.3.4 Knowledge and Awareness

The knowledge and awareness of the needs of persons with hearing loss by those individuals interacting with the study participants was reported to be limited. The individuals who interacted with participants in this study included audiologists, counselors, employers, physicians, friends and family members and teachers. Participant AM009 described her experience with her audiologist who did not have the knowledge to prescribe an FM sound field system that was compatible with hearing aids for use in her classroom. After the participant realized the sound field system that had been purchased was not compatible with her hearing aids, she tried to reach out to the audiologist for assistance, who was not willing or able to help.

But then last year uh when I had the [not-for-profit agency workplace accommodations consultant] involved in it, and so I guess it was about a year ago, yeah that would be about a year ago, last fall. Umm, [the agency] on his recommendations got a sound field system for my school, in the classroom, and we set it up. We could never get it to work. And umm [the consultant] from [the agency] couldn't ever get a hold of the audiologist, she couldn't get any answers from him. It went on for weeks, and got absolutely no satisfaction and then finally, and, and the board have received it so there was a time where they would have to pay for it right? It was over ten thousand dollars. So I don't know why I should've cared, but I did. I didn't want them to have to pay for that if it was never gonna work out. So finally after weeks of this, he finally said oh that's not gonna work, so left me high and dry. (Participant AM009)

This participant reported that her audiologist did not take into consideration the type of hearing aid she was using before prescribing her with a piece of equipment that she was told would be compatible.

Participants reported that individuals who offer counseling services for employees within companies should be aware of hearing loss and the challenges that are present amongst

individuals with hearing loss when working. This was not the case for the following participant.

...I thought I gotta go for counselling. So, I made an appointment and I sat down with the counselor and...she knew nothing of hearing loss. So I spent my first hour appointment explaining to her what a hearing loss was...I thought to myself, if you don't know what hearing loss is, then you don't know my struggles.  
(Participant AM002)

This participant reported that this interaction caused her additional stress and fatigue.

Employers are a critical player in supporting individuals working with hearing loss to access and receive accommodations. Participants reported that employers did not understand or support the requests from their employees or from the employee's audiologists and physicians. Participant AM009 explained how her employer responded and how it made her feel. "Yeah, so, I'm just exhausted. I think my employer is trying to push me into disability and part of me is tempted, 'cause I just- I'm tired. I just- I just wanna give up".

This example shows how an employer, who did not understand the accommodation needs of the employee, and the suggested solution, was perceived as preferring to remove the employee from the workplace and to place them on disability benefits rather than make workplace accommodations for the employee.

Participants also described the need for physicians to be more aware of the consequences childhood hearing loss may have on individuals. A participant explained that hearing loss, particularly at young ages, should be flagged and addressed as soon as possible.

So one of the main reasons why we were so late in getting hearing aids and everything was because our doctor wasn't very good that we had at that time, so I guess, umm, my brother and I were actually diagnosed with a hearing loss when we were born, but our doctor didn't recommend that they do anything.  
(Participant AM008)

Lastly, Participant AM002 reported that friends and family members should be more supportive and aware of what their loved ones are experiencing.

One's a director, one's- another girl has since retired. So when I was off in April, so June, and we met for drinks. We had another friend from out of town so we all got together and umm, so they just said 'look, what do you want?' Like what? I ended up crying. And they're my friends, they just don't get it. And that's my best friends, 25 years of best friends and that was their attitude. So, that was the attitude of everybody.

Participants described themselves to be very frustrated when the individuals they care about did not understand how the hearing loss was impacting their ability to communicate.

### 3.3.5 Workplace Environment

The workplace environments of the participants impacted the decisions to access resources. Participants reported that career choices, job requirements and job descriptions, as well as the employers, are all considered when deciding whether or not they should access resources. There are some workplace environments that were described as contributing to the success of some participants.

Well, and you know what, it's funny, this has been very enlightening because maybe my career choice of working from home, umm, now granted it's a good gig, you know works out well, but now I realize how its suited my handicap.  
(Participant AM005)

Participant AM005 further described that working from home in a quiet office, with no one else around made working with a hearing loss more manageable. She discussed the added benefits of only seeing her coworkers once every one or two months. She stated, "Um, good— [sighs] because I work from home, I'm only with my coworkers once a month, once every two months. And maybe this is why this job suits me so much. Because I'm at home".

Other individuals acquired hearing loss while working in careers they have had for several years. This was reported to be difficult for participants when trying to adjust to working with a hearing loss. Participant AM002 explained her experience.

Umm, maybe if you're hired and you go for an interview and say I have a hearing loss and then you start fresh. But, in my case I was already there, 10-15 years when the loss came. Umm, things they don't understand, after working four hours, you've already exhausted yourself to an eight hour day.

This participant was describing the challenges of having employers understand the changes they were going through. In some cases, participants reported that acquiring a hearing loss while actively working often required some changes to the workplace environment. The following example describes poor workplace environments and some of the challenges that Participant AM001 encountered at work.

Um, I have difficulties in my office...it's the hub of the department. The door is right at my reception window and my wireless microphone brings—picks up everything. I've played around with trying to make it...just focus on the words coming at me but not getting the noise at the door but it's al—always been a challenge to ask them not to speak or have a conversation next to me when I'm not involved.

Some of the challenges described above can easily be resolved by the cooperation and support of coworkers. Other challenges such as the experience described below by Participant AM007 are more difficult to change at the workplace level, and therefore require more resources.

It was, for the most part it was okay, but then there's a lot of machines and beeps and buzzers and when they go on and fire alarms and stuff, it's like okay well I'm pretty well pooched. I can't hear anything else, so it was challenging but I was still able to do my job, but of course fire alarms, they don't go on forever. Umm, on weekends when it's busy, I found it more challenging too because there's more background noise. And the phone was always a big challenge, doing credit services we always—well we didn't always have to call credit services for credit applications, the customers did them on the pin pad and well I wish I could say most of them were approved then you wouldn't have to call credit services. On the phone I had to always have to take the hearing aid out—the hearing aid out for that. So, and then customers and staff who speak softly, it's like can you please repeat? (Participant AM007)

This participant described one of her challenges was using the telephone. Another participant also described how the telephone became something she avoided because of her difficulties trying to use it at work. Participant AM002 stated, “After 14 years of a struggle with hearing loss, I don't do the phones”.

Some of the challenging workplace environments were created by employers or other coworkers who did not understand the effects of hearing loss. Participant AM009 described a location change in her workplace that made communication with hearing loss

more difficult, despite having had discussions with her employer about how to accommodate her hearing needs.

And about two years ago, the music room...I'm in another weird physical school. It's got pods, circular pods...And about two years ago, the music room got brought down to my pod. And, the music teacher who is extremely talented, lovely, lovely lady, refuses to close her door. So, I have to close my door all the time. And I wasn't hearing the fire alarms. I—the kids would stand up and start lining up for the door and I would say what are you doing? So, I thought, okay well this isn't good. (Participant AM009)

Some workplace environments were described by participants as busy, loud and at times fast-paced. These environments often required increased exertion and energy from participants because of the high communication demands that were created. One participant described her workplace environment and the difficulties that she encountered every day.

Um, I have difficulties in my office- it's the hub of the department. The door is right at my reception window and my [wireless microphone] brings—picks up everything. I've played around with trying to make it—um-just focus on the words coming at me but not getting the noise at the door but it's al—always been a challenge to ask them not to speak or have a conversation next to me when I'm not involved. Because I hear that conversation, the phone ringing, the patient at the window, and it's hard on my brain. (Participant AM001)

In addition to workplace environments, the home environments of participants were described. Some participants reported that they would take breaks from using their hearing aids or other assistive devices to enjoy some time in silence. Participants reported that these opportunities allowed them to relieve stress and relax. Participant AM009 stated, “I find that when I'm done working, you know being nattered at by 25 kids, umm by the time I get home, I just take out my hearing aids and just leave me alone”. Similarly, Participant AM005 explained that she took her hearing aid out as much as possible when she was at home. “Yeah, oh yeah, yeah, yeah. I would prefer it [hearing aid] out rather than have it in”.

In summary, participants described unique, individual, experiences and five overarching themes emerged based on their stories. A detailed discussion regarding these findings will be described in the following section.



## 4 Discussion

This discussion will begin by explaining the different types of resources that were accessed by participants. It will describe some reasons as to why participants may or may not have accessed particular resources. The knowledge and awareness of communication partners, employers and audiologists will be considered. Lastly, ongoing challenges that were described by participants as well as some implications will be explored.

### 4.1 Accessing Resources

The participants in this study all had accessed resources based on the definition of resource used for this study. A resource was defined as being anything or anyone that provided assistance to the individual. The types of resources that each participant accessed were varied. Some of the participants reported using no hearing assistive devices at all, while some reported using only hearing aids. Other participants reported using hearing aids, additional hearing assistive devices and a variety of other resources. Apart from hearing aids, other hearing assistive devices included FM systems, wireless microphones, bed-shaking alarms, and visual alerts. Aside from hearing assistive devices, other resources included workplace accommodations, and aural rehabilitation. Most participants who described accessing additional resources and other hearing assistive devices aside from hearing aids reported negative experiences. The experiences of the participants when accessing these resources are described in greater detail later in the discussion.

Participants who used only hearing aids reported that they were coping with their hearing loss at work and managing their daily challenges. Most of these participants were prescribed hearing aids as children and did not access further resources beyond hearing aids as an adult. One participant reported that she accessed hearing aids because she thought that was her only option and she believed she was managing well. These participants explained not wanting to share information about their hearing loss with people at work if it was not necessary to do so. Many of these participants did not reach out to employers for any assistance or accommodations as they reported feeling embarrassed or considered that they were managing well. Some of the participants who

only used hearing aids in the workplace did not believe they needed to disclose their hearing loss to anyone at work because the visibility of their hearing aids made it clear. Southall, Jennings, and Gagné (2011) found similar findings in that some of the participants in their study described not having to disclose their hearing loss at work because their hearing aids disclosed it for them. Although the participants in the current study were coping and reported little to no changes in their perceived hearing capabilities, it is possible that they would have benefitted from accessing additional resources such as workplace accommodations or aural rehabilitation. The literature states that individuals are more likely to seek help for their hearing loss if they perceive their hearing loss has worsened, the degree of their hearing loss has worsened (Knudsen, Oberg, Nielsen, Naylor, & Kramer, 2010) or they begin to experience participation restrictions related to their hearing loss (Meyer & Hickson, 2012). The findings for this current study echo the research and suggest that individuals with a hearing loss that has not changed and is marginally affecting their ability to communicate may be less likely to access resources beyond hearing aids until they experience a change in their hearing loss or a change in their social participation. If this is true, individuals with stable hearing losses may benefit from being made aware of other resources that exist prior to experiencing deterioration in their hearing status, abilities, and/or performance.

Facilitative communication strategies are included in the list of additional resources. These strategies are not necessarily something that participants accessed, however they are still considered a resource by the definition used in this study. Participants described using these strategies prior to accessing resources or in addition to accessing resources. Facilitative communication strategies, such as preferential seating choices were often described by participants as being one of the first resources that were used. Some participants used these strategies to avoid disclosing their hearing loss to coworkers or employers, whereas other participants used these strategies to improve the benefits of other resources they were using. Jennings, Southall, and Gagné (2013) reported similar findings stating that,

Participants frequently mentioned trying to move to a quieter area, moving closer to and giving your undivided attention to the speaker, getting to meetings early to get a seat close to the speaker, asking persons on the phone to speak directly into

the phone, in an attempt to improve the ability to hear. All of these strategies were employed to avoid telling the other person directly that the problem is due to the hearing loss (p. 175).

Although all participants in this study accessed resources, there may be reasons as to why some participants have accessed more resources than others and why they may have chosen to access or not to access different types of resources. The reasons that were identified in this study are described below.

## 4.2 Childhood Experiences

Childhood experiences with resources, such as hearing aids and other hearing assistive devices were described as playing a role in whether or not participants continued to use these resources. Participants who acquired hearing loss during childhood reported poor experiences with their hearing aids and other hearing assistive devices. These participants did not access additional resources beyond hearing aids and other hearing assistive devices while growing up. Participants who received hearing aids as young children reported instances of stigmatization and bullying, which caused them to not use their hearing aids or other hearing assistive devices they had growing up. Once these participants reached adulthood and entered into the workforce, they described needing their hearing aids; however they refused to try other hearing assistive devices because of their negative experiences with these devices as a child. Participants who acquired hearing loss as children were reluctant to access additional resources; however some of the participants did access resources such as aural rehabilitation and workplace accommodations in adulthood because of a change in their hearing capabilities. Based on the experiences of participants using hearing aids and other hearing assistive devices, it appears that individuals who have difficulties using or accessing these devices at a young age, have increased challenges using and accepting them when they enter the workforce. If this is true, greater knowledge and awareness within school systems is needed to improve these early childhood experiences for students with hearing loss. Eriks-Brophy and Whittingham (2013) stated that there is a,

...need for increased emphasis on the understanding of students with hearing loss and their unique educational needs in the curriculum of teacher education

programs, as well as the provision of appropriate supports to both teachers and students to promote success in inclusive classrooms (p. 64).

In addition to teachers and students, this research may also suggest that parents of children with hearing loss as well as counselors and audiologists working with children should focus on the care of the child as an individual in order to improve their early experiences. Increased knowledge and awareness among individuals working or interacting with children is needed to improve the childhood experiences of using resources and to increase the number of individuals accessing resources at younger ages.

### 4.3 Stigmatization and Acceptance

Although participants did not explicitly use the term *stigma* when describing their experiences, they described accounts of embarrassment, bullying and teasing. Most of these negative experiences occurred for participants who had acquired hearing loss during their childhood and the experiences they described occurred when they were children. Similarly, multiple research studies have found that children with a hearing loss who are integrated into general education settings are at an increased risk of social isolation, reduced self-esteem, and increased interpersonal difficulties (Cappelli, Daniels, Durieux-Smith, McGrath, & Neuss, 1995; Markides, 1989; Musselman, Mootilal, & MacKay, 1996; Nunes & Pretzlik, 2001).

Some participants also described being embarrassed to wear hearing aids through adulthood because of the way they expected they would be perceived by others. This included participants who acquired hearing loss during their childhood as well as those who acquired it during adulthood. The use of hearing aids and other hearing assistive devices may still be considered a stigmatizing characteristic of both children and adults. Claesen and Pryce (2012) interviewed participants who had been prescribed hearing aids and found that the most influential reasons for not accessing hearing aids were overall concerns about having a hearing aid such as being different from their social groups and the stigma that is associated with perceptions of old age and negative esthetics. Additionally, a study completed by Blood (1997) reported that although 75% of normal hearing participants recognized the benefits of hearing aids after trying them on, 25% of the participants reported that they would not wear hearing aids if they acquired hearing

loss “because of the perceived stigma” (p. 62). Giles and Reid (2005) reported that because social categorizations create stigmatizing groups, these groups have the ability to change with greater knowledge and understanding. With this in mind, we may suggest that individuals who perceive hearing loss to be a negative characteristic could improve their knowledge, awareness and understanding of the benefits hearing aids and other hearing assistive devices can offer individuals with a hearing loss. Meister, Grugel, and Meis (2014) used the Theory of Planned Behavior to explain the intention for individuals to use hearing aids. In addition to knowledge, awareness and understanding of the resources, individuals must also have a positive attitude towards accessing resources, have social support from friends and family and believe they are in control of the decisions to access these resources. Within clinical practice, the Theory of Planned Behavior model can be used when openly discussing the possibility of resources such as hearing aids or other hearing assistive devices with patients and their significant others (Meister et al., 2014). Furthermore, a positive attitude towards hearing aids was also found to be the most influential factor when individuals were deciding to seek help for their hearing loss and adopting hearing aids (Meyer, Hickson, Lovelock, Lampert, & Khan, 2014). Kochkin (2017) reported a list of possible reasons for not using hearing aids which also included stigma of hearing loss as well as inadequate information about hearing loss, misdirected medical guidance, unknown importance of hearing, misconception that hearing aids do not work, failure to trust hearing aid dispensing professionals, unknown value of hearing aids and the high costs associated with the purchase of hearing aids. Addressing these factors may be an early step in removing the existing stigma and improving the number of individuals who are accessing resources when they first notice a change in their hearing abilities.

The stigmatizing characteristics that are still present may contribute to the fact that participants described the process of accepting a hearing loss and accessing resources to be difficult. Héту et al. (1990) stated that “The reluctance to acknowledge hearing difficulties is part of an adaptive process governed by the fear of stigmatization” (p. 273). Participants acquiring hearing loss as adults reported many different emotions after receiving hearing test results. Some participants reported responding with denial. They stated that they refused to listen to what the audiologist was telling them and tried to

ignore the results. Denial was also found to be the first category in the 'Classification of difficulties in acknowledging hearing problems as expressed by victims of occupational deafness' that was reported in a study by Héту et al. (1990). Often, participants described it took time to process the information provided by the audiologist about the results of a hearing test and the need for intervention before they were able to access further resources. Other participants reported that they went into the test assuming that they had a hearing loss, yet they still reported having difficulty accepting their hearing loss once it was confirmed by an audiologist. This suggests that individuals may perceive hearing loss as a negative characteristic that defines individuals. They may not be aware of the effective resources and accommodation options that are available.

When acquiring hearing loss as an adult, some participants described receiving hearing aids soon after they were recommended by an audiologist. There were some cases when participants reported that additional factors such as financial limitations or psychological readiness played a role in delaying access to the resources that were recommended. One participant reported that she accepted the audiometric results soon after she received them and described that she was unable to afford hearing aids at that time. She explained that she was required to save money for a couple of years before being able to purchase her hearing aids. Although there are some financial supports available, participants appeared to be unaware of these options or did not qualify for the financial aid. Another participant described that she was not ready for hearing aids and chose not to purchase them after her audiologist explained how they would help her. This suggests that acceptance may be delaying some individuals from purchasing hearing aids; however it may not be a factor for all individuals. Participants, who acquired hearing loss during childhood, described not being involved in the decision to receive hearing aids because they were too young. They refused to wear them once they were prescribed.

In addition to hearing aids, some of the participants described using other resources. Participants described that when they experienced unexpected or sudden changes to their hearing loss, they often concluded that hearing aids alone were not sufficient, causing them to access additional resources. Participants described being more accepting of these resources than they were when they considered the hearing aids alone to be sufficient.

Participants with lesser degrees of hearing loss that were stable, and had work environments that had fewer changes in communication demands, reported managing with solely their hearing aids or no hearing aids at all. They reported not wanting to access other resources. These findings suggest that individuals are not likely to reach out to access additional resources aside from hearing aids until they experience a sudden change in hearing loss, an increase in workplace demands, or an unexpected event causing them to feel upset or embarrassed. Further information regarding available resources may be helpful for individuals with hearing loss in order to access resources prior to experiencing a sense of urgency caused by an unexpected event. A study by Southall, Gagné, and Leroux (2006) reported that one of the factors influencing the use of assistive technology for persons who have a hearing loss is accessibility, i.e., a persons' awareness and access to information regarding hearing assistive technologies beyond hearing aids. Southall et al. (2006) found that the majority of participants in their study reported that lack of knowledge was a barrier to accessing assistive technologies for hearing loss.

The stigma that exists surrounding hearing loss and the use of hearing assistive devices may contribute to an individual's decision to access or not access resources as well as what resources to access and when to access them (Southall et al., 2011; Héту et al., 1990; Wallhagen, 2009).

#### 4.4 Knowledge and Awareness of Others

One of the main findings of this study is that individuals, whether they are interacting with persons with hearing loss or not, require greater knowledge and awareness regarding hearing loss and the resources that are available. The participants described many different situations when interactions with other individuals created increased challenges. Participants reported interacting with many people who they described as having little to no knowledge regarding hearing loss. This suggests that individuals who are interacting with people who have a hearing loss require further education and knowledge about the communication needs of persons who have hearing loss in order to improve communication accessibility. The specific examples that were provided by participants in this study included teachers, counselors, physicians, and significant others.

Teachers may require more knowledge about childhood hearing loss and how this affects a child's learning. Albert (2007) states that, "Any child with a persistent hearing loss will benefit from experienced, professional support in the educational environment to ensure that teachers are aware of the extent of the loss and how best to overcome it" (p.24).

Individual and group supports regarding bullying and stigmatization could be implemented for children with hearing loss. Seminars, workshops, online tutorials or meetings could all be considered as options for teachers.

Counselors may require increased knowledge of how to talk to individuals with hearing loss. An increased understanding of hearing loss and the use of hearing assistive devices, such as hearing aids may benefit counselors, human resource personnel, and worker advocates. Workplace counselors and human resource personnel may require more training in accommodations and resources available for employees working with a hearing loss.

Physicians should be aware of the role they have when working with individuals with hearing loss as well as their role when working with hearing healthcare professionals such as audiologists and hearing instrument specialists. They may need to work with employers or provide documentation about their patient regarding their hearing loss. In a study by Wallhagen and Pettengill (2008), participants reported that their primary care providers rarely assessed or asked about their hearing. The importance of their hearing challenges would often be minimized and symptoms would not be followed up on (Wallhagen & Pettengill, 2008). It is important that physicians understand that hearing loss can become a debilitating challenge that can negatively impact one's job performance if the appropriate accommodations are not made. Similar to the findings of Shaw, Jennings et al. (2013), it is suggested that an increase in professional collaboration will improve the care of individuals with hearing loss.

Individuals who care about their friend or family member with a hearing loss can have a positive impact by providing support. Wallhagen (2009) stated that "having a spouse or partner who perceives hearing aids in a negative way can influence decisions in subtle ways, including not providing active support for obtaining aids" (p. 72). In contrast, when



family members and loved ones recognize the participant's hearing loss and are supportive and motivating, the individual with hearing loss is more likely to access resources such as hearing aids (Lockey, Jennings, & Shaw, 2010). A study by Meister et al. (2014), that used the Theory of Planned Behavior as a framework to better understand the intention to use hearing aids, described that intention to access and use hearing aids was higher if the *subjective norm* (perspective of loved ones) was favorable. Hearing aids were the main focus of the study; however it would be beneficial to understand if the findings are similar when deciding to access other resources. Friends and family members may be able to play more of a role in their loved one's experiences with hearing loss. They can attend more appointments, ask questions, gain knowledge about the hearing loss and communication strategies, and remain as patient as possible when interacting with their friend or family member who has a hearing loss.

The experiences that the women in the current study described when interacting with various individuals played a role in their decisions to access resources as well as the outcomes that were shaped by these decisions. Individuals who were described to be interacting with the participants can be viewed as 'gatekeepers' based on the stories in this study. When interacting with these individuals, participants described the individuals to be either facilitators or barriers to their decisions to access resources depending on their past experiences. Often when the experiences were negative, the participants described increased difficulty accepting their hearing loss and accessing resources. This suggests that increased knowledge and awareness is required for all individuals interacting with a person with hearing loss. Similarly, it was suggested that there is "a need to educate employers, employees and healthcare workers who interact with individuals with hearing loss about the services and supports that are available" (Jennings & Shaw, 2008, p. 292).

## 4.5 Employer Involvement

In addition to the individuals described above, employers were also described by participants as displaying limited knowledge and awareness of the impacts of hearing loss in the workplace. Participants who reported accessing multiple resources, such as workplace accommodations explained their experiences of speaking with employers

about their hearing loss. Once employers became involved, participants described that the daily challenges at work and at home became increasingly difficult. These participants reported having difficulties with their employers after choosing to disclose their hearing loss. Participants explained that when they went to their employers for information regarding workplace accommodations, they were treated with a lack of care, compassion and respect. Participants reported that employers who were aware of the employee's hearing loss did not know the workplace accommodation rights of their employees and often did not follow what they had been asked to do if workplace accommodations were arranged. In a study looking at the perspectives of employees, supervisors and Hearing Conservation Program (HCP) managers, very few supervisors and HCP managers were able to describe any accommodations that could be accessed for people with hearing loss (Morata et al., 2005). Most workplace environments can be easily altered in ways that accommodate the individual's needs, however findings from the current study reported that these changes were not occurring in many cases and that employers were not aware of the challenges their employees with hearing loss were facing.

Participants described employers as being unsupportive and not understanding of the challenges their employees were facing. One example that was reported by some participants was that employers and other coworkers did not understand that each individual with hearing loss is going to have different challenges. Hearing loss is not an all or nothing situation that is similar to everyone. A participant in a study by Southall et al. (2011) described similar challenges when trying to describe 'partial' hearing loss. He explains that the general population understands normal hearing and clinical deafness however everything in between is not clear. Many people do not understand why individuals with hearing loss can hear some things, but not other things.

Employers were also not aware of the needs of their employees. After disclosing her hearing loss to her employer, one participant described that her job quickly changed because her employer did not believe she could remain in the same position. This change in jobs led to a change in her financial benefits which meant she needed to make a rushed decision to acquire hearing aids. The short period of time that was provided by the employer made it very difficult to try multiple options in order to find something that best

suited her needs. This suggests that employers do not understand that the abilities of individuals working with hearing loss do not necessarily change; the ways of doing things may simply change. It also suggests that employers do not have adequate knowledge of how long it can take to acquire suitable hearing aids or other hearing assistive devices. If an important decision such as this is made in a short timeframe, there is the possibility that the individual accessing the device does not receive a device that is optimal for his/her communication needs. This may lead to an individual using the device less than is required or benefiting less than possible from its use. Additionally in a study by Jennings and Shaw (2008), one of the participants described the lack of assistance from her employer. She described having to find information and acquire hearing assistive devices on her own without the help from her employer (Jennings & Shaw, 2008). Most participants in the current study did not receive help from their employers regarding information or accommodations. They often had to reach out themselves to external organizations, employee nurses or human resource employees for additional assistance and information.

In the experiences of these participants, employers showed very little support and empathy. This may suggest that employers should improve their understanding of hearing loss as well as their understanding of the challenges that accompany it. Morata et al. (2005) stated that within their study, “no program manager indicated that hearing impaired workers may need special accommodations in the workplace” (p. 540). This statement supplements the findings of this research by describing the lack of awareness of some employers.

Although it was reported that the accommodations process was poorly addressed by employers, some participants also described their own lack of knowledge in this area. They were not always aware of what they could ask for, or needed to ask for from their employers. In order to be successful when inquiring about workplace accommodations, it is important to know what types of challenges you are having and what types of resources will be of assistance. A participant in a study by Jennings et al. (2013) reported that it is important to have a knowledge base regarding accommodations, rights and technologies and to present one’s strengths to an employer. Participants often reached out to external

organizations for assistance in working with their employers. Both employers and employees may benefit from greater familiarity with the workplace accommodations available and the resources that can be accessed within the workplace.

One participant described having a positive experience with one of her employers. Although she also reported negative experiences with other employers, she explained having a supportive and understanding relationship with her employer at one of her workplaces. This workplace provided services for individuals with disabilities. The employer and other employees were knowledgeable and understanding of the challenges that may be present when working with a variety of disabilities, including hearing loss.

Overall, most participants stated that their employers required further knowledge and education on the challenges that individuals experience while working with a hearing loss and the available resources for individuals with hearing loss. Employers and other employees should attend seminars, workshops, online tutorials or meetings to improve their awareness of hearing loss and the type of accommodations that would benefit a person with hearing loss. A focus group from a past study described the possibility for an educational program to be implemented for employees and employers (Morata et al., 2005). These suggestions may be used as a step forward in producing a greater knowledge base in this area for both employers and employees. This may improve the experiences of individuals working with a hearing loss.

Employers are required to be familiar with the Accessibility for Ontarians with Disabilities Act (AODA). In Ontario, all organizations with one or more employees must abide by the AODA rules and regulations. This act was put into place for anyone living with either a visible or non-visible disability (Accessibility for Ontarians with Disabilities Act [AODA], 2005). It is important for all employers and employees to be aware of this act and to know their rights and responsibilities. This act is a way of protecting all individuals with disabilities who are working or accessing goods or services (AODA, 2005).

## 4.6 Experiences with Audiologists

There were positive and negative experiences described by participants when discussing interactions with their audiologists. The participants who reported positive experiences noted that their audiologists were very helpful, supportive and open to discuss any challenges they were going through. These participants described being comfortable speaking to their audiologists and believed to be receiving optimal care. The experiences were described as being positive when the audiologists were perceived as spending sufficient time with their patients. Participants perceived they were receiving individualized care. These positive experiences appeared to minimize everyday challenges for these individuals.

Other participants reported that their audiologists were not providing the level of care that they had anticipated. They described feeling ignored, misunderstood, and alone. Participants described that they experienced very little support with their hearing aids and other devices during their appointments as well as during the time in between their scheduled appointments. One participant, for example reported that she was prescribed a sound field FM system for her workplace that was not compatible with her hearing aids. This may have been because the audiologist did not take the time to understand her individual circumstances and the resources she was already using. This suggests that audiologists may need to spend more time explaining the different types of resources such as hearing aids and other hearing assistive technologies and how they will be beneficial for each individual, the environment in which they are working and their lifestyle. In addition, it is important to effectively communicate and work closely together with the employee, employer, and other persons in the workplace to ensure that accommodations recommended and purchased are compatible with existing technology and with the individual. A participant from a study by Jennings and Shaw (2008) reported that there were not any efforts made by professionals to assess communication demands and barriers in the workplace or suggest possible accommodations. Shaw, Jennings et al. (2013) described the lack of knowledge that audiologists have surrounding workplace accommodations and lack of ability to assess various workplace environments. The study describes the lack of graduate education being provided to incoming audiologists

regarding workplace assessments and how experiences with audiologists could be improved by providing audiologists with additional education (Shaw, Jennings et al., 2013). Other studies have shown that by providing more individualized care, patients experienced greater success when coping with their challenges at work and at home. There is a benefit from a shared understanding and appreciation for the individual's unique experiences and journey (Mattingly, 2006). When interviewing older adults, Southall et al. (2006) reported that a "lack of awareness of and accessibility to HAT (assistance technology for persons who have hearing loss) seem to be barriers that could easily be addressed by hearing health professionals" (p. 258). Participants in the current study reported similar experiences. Participants explained that once a hearing loss is diagnosed, and hearing aids or other hearing assistive devices have been prescribed, there needs to be more time spent on the delivery of information regarding the resources provided as well as additional resources that may be helpful. Multiple studies reported that the development of patient-centered goals and plans based on the experiences of patients would likely improve patient satisfaction (Layton, Moss, & Morgan, 1998; Manchaiah, Stephens, & Meredith, 2011; Mattingly, 2006).

Lastly, more information pertaining to additional resources available outside of the audiology clinic could be provided. The experiences of the participants in this study suggest that audiologists may be able to act as a more reliable and helpful resource for their patients if the audiologists attended to the specific needs of the participants. Jennings and Shaw (2008) similarly suggested that "It is critical that audiologists provide not only instrumental supports such as hearing aids, but also information and opportunities for individuals with hearing loss to learn how to adapt and cope with the impact of losses" (p. 292).

## 4.7 Ongoing Challenges

### 4.7.1 Emotional and Physical Strain

Throughout the term of the study, participants described how they experienced many negative feelings and emotions related to their hearing loss. Some of the emotions that were described by participants included feelings of embarrassment, frustration, guilt,

nervousness, worry, stress, and loneliness. In addition to feeling emotionally strained, many participants also described feeling exhausted and disabled. These emotions were described as being ongoing challenges for the participants. Participants described having many different responsibilities such as working, supporting a family, going to school, and attending social events. Participants reported that trying to accomplish these things with a hearing loss became more exhausting and challenging, and this often lead to increased negative feelings and emotions. This suggests that accessing resources does not always remove these negative feelings and emotions, however appropriate knowledge and awareness of the resources available, as well as the possibility of reducing the present stigma, may lead to significantly decreasing these negative feelings and emotions.

#### 4.7.2 Group Settings

All participants described having increased communication difficulties in group settings. These settings existed both at work and outside of work. Some of the situations that participants mentioned included work meetings, listening and teaching in a classroom, dinner with friends and family, and recreational events. These environments were described as loud and busy. Past research shows similar findings. The most difficult work situations for hearing impaired individuals typically involve group settings including training sessions, staff meetings, and work-related social events (Laroche, Garcia & Barrette, 2000; Scherich, 1996) Participants from this study reported increased challenges when having a one-on-one conversation in these settings, resulting in increased fatigue. When individuals with hearing loss are using other cognitive resources such as visual processing when trying to understand speech (i.e. speechreading), increased listening effort is required, which often leads to increased mental fatigue (Baldwin & Ash, 2011, Hornsby, 2013; McCoy et al., 2005). Many participants described that they began avoiding situations at work and at home that they believed required too much energy. Increased fatigue and avoidance of social situations also lead to increased negative feelings and emotions for many participants. Some participants reported trying or using other hearing assistive devices such as wireless microphones in addition to their hearing aids in these situations. Others described trying to manage with only their hearing aids. There were some participants who described using devices that worked for them in group

settings, but most participants reported that they were not managing well in these situations, even when using additional resources.

Depending on the importance and significance of attending group situations, individuals may be more or less motivated to access multiple resources in hopes of finding something that helps them to remain actively involved and able to effectively communicate in these situations. The findings of this study suggest that although individuals may be accessing resources for these types of situations, the ongoing challenges of communicating in group settings remains a problem for people with hearing loss.

#### 4.7.3 Telephone Use

The telephone was described by participants as another ongoing challenge. Participants described talking on the telephone to be near impossible at times, however very few of them reported to be using, or to have tried telephone related assistive devices.

Participants stated that the reasons for not using a telephone related assistive device included not wanting any additional devices that may cause them to be perceived as being old or disabled, not wanting another device because it is too much work, and having poor past experiences trying to use a telephone amplifier. The reasons for not wanting additional devices or not wanting to be perceived as old, reinforces the stigma of hearing loss and hearing assistive devices and may suggest that individuals are not entirely aware of how the devices work and look. If this is the case, individuals may require increased awareness of the technology that is available. The poor past experiences that were described by participants may suggest that participants did not properly learn to use the devices or were not using a device that suited their daily needs. Individuals accessing these types of resources may benefit from additional information and assistance when trying them for the first time.

#### 4.7.4 Demands and Control in the Workplace

Group settings and telephone use may be both associated with a specific type of job, however depending on the control over workplace tasks and the level of demand of these tasks, the experiences of individuals working with a hearing loss will differ. Some participants reported higher workplace demands, and described the challenges of working



with a hearing loss in those environments. They reported having very little control in formulating the decisions related to their tasks and responsibilities. Danermark and Gellerstedt (2004) described that both high and low demand jobs that are characterized by low control are related to increased health problems for individuals with hearing loss. Their research found that 30% of working women with hearing loss have jobs that are high in demand and low in control, relating to the greatest risk of health problems and lack of wellbeing (Danermark & Gellerstedt, 2004). Although some participants described the demands and their personal control of their jobs, this was not explicitly asked and not all participants provided these details. Some of the participants in this current study who reported high demand, low control jobs, also reported high levels of stress, fatigue, and frustration, relating to a lower well-being. It would be valuable to understand if the health and wellbeing related to workplace demands and control over one's job are related to the decisions to access resources.

## 4.8 Additional Information

### 4.8.1 Personal Resources

Despite many ongoing challenges and negative experiences described by participants, some positive outcomes were also described. Although some participants reported that employers provided very little support overall, there were participants who stated that they did receive the accommodations that were requested and were managing better due to workplace accommodations. These participants were able to use themselves as a resource and advocate for themselves. They worked with additional organizations and their employers to develop workplace accommodations that all parties agreed upon. For example, one participant described that her quickly declining hearing loss required her to access multiple resources in a short period of time. This participant was satisfied with the majority of the resources that she accessed because they improved her ability to communicate at work and at home. This suggests that it is possible for the quality of life of individuals to improve and for the challenges related to working with a hearing loss to be minimized when asking for and receiving accommodations from an employer. With this in mind, most of the participants who received their requested accommodations at work still reported having little to no support from their employers. The findings from

this study suggest that although workplace accommodations can be helpful for individuals, the process of receiving these accommodations remains difficult.

Another participant described how she was able to tailor her career choices to accommodate her strengths and weaknesses of working with a hearing loss. This is another example of how this participant became her own resource. This participant described the experience of having a hearing loss as a child to be beneficial to her as an adult. This finding is in line with that of Zaitzew (2016) whose work described individuals who acquire hearing loss during childhood as benefitting from reduced psychological stress levels because they have had the opportunity to establish a lifestyle that allows them to manage their hearing loss.

#### 4.8.2 Resources at Home

Participants described using some resources at home that they do not use at work. Resources that participants reported using in their homes included hearing assistive devices such as bed-shaking alarms, and visual door bells. Closed-captioning on the television was also described as an additional resource many participants used within their homes. Participants described that these resources were sometimes not required at work, not available at work, or they were not comfortable using them outside of their home. In addition, some of the resources that were described by participants could be used at work, however in a slightly different way than they are used at home. For example closed-captioning could be used when working with different computer programs or watching informational videos at work. These situations were not described by participants in this study. It is important that individuals with hearing loss understand the variety of ways in which different resources and devices can be used in different environments.

In contrast, resources such as hearing aids that are used regularly at work by participants were sometimes not used when at home. Participants described needing a break from listening once they got home from work. Although resources such as hearing aids help to minimize listening effort at work, most individuals working with hearing loss are still exhausted at the end of the day. Similar to the results reported by Lockey et al. (2010),

many participants in this current study also explained that they enjoyed the silent time at home. This may suggest that individuals with a hearing loss may benefit from listening breaks at work. Breaks and times of silence throughout the day may be helpful in maintaining a high quality of life for individuals with hearing loss.

#### 4.8.3 Uncorrected Hearing Loss

Although some participants reported accessing resources such as hearing aids as soon as they were prescribed, some participants delayed going for their first hearing test or delayed accessing recommended resources such as hearing aids. There is a possibility, based on this study that if a hearing loss is ignored and the appropriate resources are not accessed, the challenges may continue to grow and the negative feelings and emotions described earlier may multiply. If emotional and physical strains continue to grow, this may lead to increased difficulties both at work and at home. The effects of the previously described tasks will become increasingly draining. In a review of the literature on the negative consequences of not using technologies for hearing loss when they are needed, Arlinger (2003) concluded that, “Uncorrected hearing loss gives rise to a poorer quality of life, related to isolation, reduced social activity, a feeling of being excluded, and increased symptoms of depression” (p. S20). This suggests that individuals should do their best to access resources as soon as they notice changes in their hearing.

#### 4.8.4 Volunteering for this Study

Throughout the study, some participants discussed the reasons they responded to the request for research participants, and why they volunteered to participate in this study. If participants had not explained their reasons for participating in this study by the end of the second interview, the researcher asked this explicitly. Most of the participants in this study reported that they experienced significant challenges and wanted to try to minimize these difficulties for individuals in similar situations. They also expressed the desire to let individuals who are having difficulties know that they are not alone and that they can succeed. Many participants expressed their appreciation to participate in the study and to have their story accessible to the public. This study allowed individuals the opportunity to

share their stories in a way that can help improve awareness of the challenges related to working with a hearing loss.

## 4.9 General Discussion

The main findings from this research that may be used to guide future research and have implications for individuals working with a hearing loss will be discussed. These include, participants not accessing resources beyond hearing aids until they experience an unexpected change or event; participants having negative experiences once they access additional resources such as workplace accommodations, which require disclosure of their hearing loss to employers; and many individuals require greater knowledge and awareness surrounding the needs of persons living and working with a hearing loss.

Participants in this current study described not accessing resources beyond hearing aids during times when they believed they were able to manage hearing-related challenges. Participants who did access resources beyond their hearing aids did so after experiencing a particular event, change in hearing, or emotional crisis. Southall, Gagné, and Jennings (2010) found that participants seek help when they believe that negative factors in their environments far outweighed the positive factors or when positive factors outweighed negative factors. In other words, “The situation had seemingly become unmanageable, resulting in the triggers or prompters to seek help” (Southall et al., 2010, p.812). In the current study, negative experiences were described by participants as often leading to disclosure of their hearing loss in order to access further resources such as workplace accommodations. This concept is similar to the findings of Shaw, Tetlaff, Jennings, and Southall, (2013) which described the social processes or strategies that workers with hearing loss use when they experience a change or challenge within the workplace. For example, Shaw, Tetlaff et al. (2013) reported that disclosure of a hearing loss became essential when job performance was at risk. Workers use strategies such as self-advocacy or self-accommodation in order to help them disclose their hearing loss and manage their work responsibilities (Shaw, Tetlaff et al., 2013).

Although research has recommended that it can be beneficial for workers with invisible disabilities such as hearing loss to self-disclose in the workplace (Lingsom, 2008)

participants in this study reported different outcomes. Lingsom (2008) reported that disclosure may be beneficial in altering workplace demands, presenting one's self in a positive way by highlighting personal strengths, and in lessening social pressures both inside and outside of the workplace. In addition, concealing a hearing loss within the workplace can consume cognitive resources (Smart & Wegner, 1999), increase stress levels (Major & Gramzow, 1999) and prevent employees from accessing accommodations (Hétu, 1996). According to the narratives of the women in the current study, this was not always the case. Some participants who reached out to their employers and disclosed their hearing loss reported increased challenges at work and very little assistance when trying to improve their workplace environments. Participants in a study by Southall et al. (2011) reported that disclosure of a hearing loss in the workplace often occurs as a last resort. The current research study has shown that the benefits of accessing resources at work for persons with hearing loss is not universal. The negative experiences that have been described by the participants in this study indicate that within the workplace, employers and coworkers require greater knowledge, awareness and understanding of the needs of employees working with hearing loss. They must also be more aware of the ways that they can help these individuals continue to succeed in the workplace.

Accessing resources beyond hearing aids such as workplace accommodations should be an early step that individuals with hearing loss can take without being concerned about stigmatization. Individuals with hearing loss continue to work without accessing resources and some individuals who have accessed resources have experienced increased challenges at work after doing so.

The experiences that participants described in this study highlight the challenges that exist with the process of accessing resources. The process of not knowing who to talk to, when to talk to them, and where to find information may be an ongoing problem.

#### 4.10 Reflection on Methodology

The narrative methodology that was used for this study was effective as it elicited personal stories of the women who participated in a way that was chosen by them. This

study was undertaken to gain an understanding of why some women have accessed different resources and why some women may have not accessed any resources at all. The narrative methodology allowed for participants to tell their stories without feeling obligated to answer specific questions or follow a set framework. Objective methods and measurements were not used in this study as they limit the type and depth of information that can be collected from participants. Objective methods such as questionnaires are not open-ended because they include limited questions and responses. Objective methods and measurements do not allow participants to explain their experiences, thoughts, or their emotions in various situations, or describe why they believe they acted in specific ways. By using narrative, participants were able to describe what they thought was important to them. The study outcomes are relevant and applicable because the subjective methodology that was used relates well to the open-ended subjective purpose of this research study, which was to understand about accessing resources for hearing loss through the stories of eight women who are working with a hearing loss.

The narrative methodology became a resource in itself for the participants in that the participants were asked to reflect on their experiences throughout the study. One participant acknowledged this when she explained that participation in this study was a step forward in her decision to purchase hearing aids.

Participants expressed having difficulty following the narrative format during the initial interview. Narrative interviews are designed to be open-ended and unstructured. This is often a new concept for people because they are most familiar with interviews that follow a question and answer format. Participants required more prompting than was expected early on in the initial interview. Participants were often stuck for words and ideas as to what they wanted to talk about. As the sessions progressed and participants learned more about the narrative interview process, less prompting was required. Participants also required less prompting during the second interview as they were able to reflect on the first interview and read through their story that was written in narrative format by the researcher prior to beginning the second interview. Participants reported that having this additional time at home allowed them to think about what they wanted to discuss ahead of time. In order to potentially lessen the amount of prompting required by the researcher

during the early interview stages, more information regarding the process of narrative interviewing could be sent to participants prior to the first interview session instead of only discussing this during the first interview session. This would allow them time to think about what they wish to discuss and understand ahead of time what is expected. On the other hand, this initial difficulty did not prolong or change the data collection process.

This study only included women. Further research including men would be beneficial in this area to understand if men have similar experiences related to accessing resources when working with a hearing loss.

The sample of participants in this study may be considered limiting as participants all had some common traits. All of the participants that were interviewed accessed some type of resources, whether it was hearing aids, hearing tests or participation in this study. There were not any participants interviewed who were having difficulties at work and had refused to reach out to anyone. All participants in this study expressed interest in participating and had stories to share about the resources they had accessed. Based on the definition of resource used, participation in this study was considered a resource and therefore there was no possibility of reaching out to individuals who have not accessed any resources.

The data for this study is qualitative in nature and therefore has been interpreted by the researcher and research team. This may not be interpreted the same way by the participants or by other readers. The results therefore cannot be generalized and it is generally accepted that the aim of qualitative research is not to generalize findings beyond the participants of a study (Onwuegbuzie & Leech, 2007). Member checking was used during this study to minimize the gap between the researcher's interpretations and the participant's interpretations. Participants read through the stories that were created by the researcher prior to the second interview in order to ensure accuracy. During the second interview, the researcher and participants discussed any changes that needed to be made.

## 4.11 Quality Considerations of Methodology

Reliability and validity have been considered to be the primary means for determining the quality of any research study (Bailey, 1996). More recently, it has been explained that these criteria are insufficient when evaluating a qualitative study (Lincoln & Guba, 1985; Mishler, 1990). A new set of criteria may need to be used to evaluate qualitative research (Lincoln & Guba, 1985; Mishler, 1990). Narrative studies vary significantly in how they are developed, implemented and analyzed. The criteria developed by Tracy (2010) describing eight different criteria for ‘excellent qualitative research’ were used to evaluate this study. These criteria include worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence (Tracy, 2010). This study explored a worthy topic, as it is relevant, timely and significant within today’s society. Rich rigor is demonstrated by the appropriate interviewing procedures that were used for the research question. Also, the researcher collected interesting and significant data relating to the study which ensured rich rigor. As previously described self-reflexivity was used by the researcher. This ensures that the study is sincere and honest. In addition to self-reflexivity, member checking was also used throughout the study. This demonstrates credibility in the study. The findings of this study have the potential to be valuable and transferable across different populations or settings, ensuring resonance. Although, not all workplace environments or types of individuals were described, the results from this study are supported by previous research studies and can be transferable in similar situations that have varying circumstances. Significant contribution is demonstrated by the suggestions to improve the knowledge base of individuals with and without hearing loss. To validate that the study is ethical, it was approved by the Research Ethics Board at Western University. Lastly, the study used the proposed methods that were first identified to develop findings that are consistent with the research question. This demonstrates meaningful coherence. According to the details for each condition, this study meets all of Tracy’s (2010) “Eight ‘Big-Tent’ Criteria for Excellent Qualitative Research”.



## 4.12 Societal and Clinical Implications

This research can be used as support for future research regarding reasons for accessing resources by individuals with hearing loss. This study included the stories of eight women who self-selected to be participants. Many of the women described their frustrations and negative experiences. It is not known if these experiences are similar for individuals who did not participate in the study. The stories of more individuals should be heard to understand if the results from this study are common amongst other individuals.

The stories of these eight women can be used to guide future research for clinical practice. Participants reported that their hopes for clinical implications are to ensure that practicing audiologists allocate sufficient time and resources to each patient. Some participants in this study explained that this was not what they experienced and that they believed some audiologists prescribed a hearing aid or hearing assistive listening device and sent the patient home with very few instructions or little ongoing support.

To my knowledge, this study is the first narrative research study that seeks to understand the stories of women working with a hearing loss relating to their decisions to access resources. Past studies have looked at the decisions to access hearing aids as well as the decisions to use hearing aids; however this study sought to understand the decisions to access all available resources related to hearing loss.

## 4.13 Conclusion

In order to gain as much knowledge and awareness as possible regarding the narratives of persons with hearing loss, qualitative research in this area should be expanded. Some questions that may be studied in the future are listed. Are there similarities or differences between the stories of men and women? Are there similarities or differences between the stories of other persons working with a hearing loss? Are the stories of individuals working in similar environments similar or different? What are the stories of individuals who choose not to access any resources? How can we improve the knowledge and awareness surrounding hearing loss in individuals such as employers, counselors, and teachers? How can we improve the overall knowledge and awareness of hearing loss in

our society? Will this improvement of knowledge help remove the stigma of hearing loss and hearing assistive devices? Are there similarities or differences in every day challenges depending on the age when individuals acquired their hearing loss? Are there some resources that have been described as being more successful for participants?

The findings from this study have the potential to increase understanding of how to improve the quality of life of individuals working with a hearing loss. Findings can be used to increase knowledge and awareness of the impacts of hearing loss on women who are working. This study begins to construct a knowledge base for further research that will help remove the stigma of hearing loss and in turn improve the quality of life of individuals living and working with a hearing loss. The findings from this study provide a step forward in improving the negative experiences that some of these women described. By doing so, it is hoped that the individuals in similar situations will be less likely to have negative experiences in accessing the resources they need within the workplace.



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## Appendices

### **Appendix A: Story Example**

I am 50 years old. I am a receptionist. I am a team assistant, and I am the first point of contact for my department. I work a 40 hour work week; Monday through Thursday. During the day, I take a 15 minute break in the morning, a 30 minute lunch and then two-15 minute breaks in the afternoon. This is my down time that allows my brain to rest and to settle down. Although I do have Fridays off, my days are very long and exhausting, especially when dealing with a hearing loss.

I first began to notice my hearing loss about eight years ago. I just felt as though something wasn't right. I began to notice myself missing parts of what people were saying and was having difficulty hearing people during meetings. When I reached the point where I felt that I was missing important information, I went to a local clinic for a hearing test. I took this step by myself and did not inform my doctor prior to getting the test. I was then directed to see my family doctor, who then referred me to an ear-nose-and-throat specialist out of town. After seeing the specialist, I was referred to an audiologist closer to my home. After being told that I did in fact have a hearing loss and that I needed hearing aids, I was ultimately shocked at the news, even though I suspected that was the case. It is one of those things that even when you think that may be the case, it doesn't become real until it is confirmed. It was good to know that I was not going crazy and that I was getting the help I needed, but it was frustrating to not have answers as to why this was happening to me at such a young age. I began thinking back, looking for possible causes: headphone use, cellphone use, loud music, hereditary origins. The answer was not clear. The audiologist recommended I get hearing aids because I had gradual hearing loss that was likely to get worse. I followed these recommendations and received hearing aids right away. I was afraid of people being able to see them; however my audiologist was amazing and explained the different options for me. I was able to start with the ones that went inside my ear. My hearing loss started out as mild, then went to moderate, then severe and is now profound. I have not been given a reason as to why my hearing loss started, nor why it has declined so quickly.

Early on, while I was having these tests done and seeing different doctors, I was not able to go to my employer to explain my situation. I was embarrassed. I didn't want them to think that I was not capable and that they needed to get rid of me. When it reached the point where I felt I needed some help, my audiologist suggested that I should go to a local agency that has employment consultants that specialize in the needs of persons with hearing loss in the workplace. The employment consultant set up a meeting with my employer as well as the employee health nurse to come into my workplace and look at my work environment. They also had me send a letter to coworkers on my team to explain my situation and give them some information about hearing loss and strategies that can be used to help us both communicate better. A workplace assessment was completed and recommendations were given to my employer and employee health nurse. The assessment was very well done. An employment consultant from the agency came to my work and met with my boss, the employee health nurse and myself. As a group, we walked through the areas where I work, including my office, meeting rooms, and team spaces. Many of the recommendations were altering how things were done in meetings or changing how I did minutes. The employment consultant recommended that I should no longer be taking minutes and gave some suggestions if I was still required to do so. There was a lot of explaining about how to communicate during meetings and how to help me follow along easier. Suggestions such as taking lots of breaks, explaining new subject areas as they were being discussed during meetings, and repeating final outcome decisions throughout the day for me to better understand.

I understand there were some workplace accommodation suggestions that I know are not feasible such as lowered ceilings or carpeted floors; however it is some of the more basic ones such as sound barriers that I am frustrated with because there has not been any progress. Another workplace accommodation that has not yet been done is when I have a one-on-one meeting, a summary of that meeting should be emailed to me. I feel that any specific instructions that I need to know about, should be emailed to me. This has never been done even though my boss was told this needed to happen.

I have had several different pairs of hearing aids that have continuously become stronger and, unfortunately, larger due to my increased loss. I currently have very strong hearing

aids that I have only had for about a year. I have had good luck with these hearing aids thus far. I do need to get new molds made next week because my current molds are becoming too loose as I am trying to lose weight. I attend all of my appointments and take the best care of my hearing aids as I can. I do the best I can to hear as well as possible, given my situation. I use a device (it hangs from a cord I wear around my neck) that directly connects my hearing aids wirelessly to my TV and cell phone. I was recently able to place a telephone call via my cellphone and the device's Bluetooth connection and had a telephone conversation with a doctor from one of the London hospitals.

I feel as though my work life is most impacted by my hearing loss. Although it does influence my home and social life, my friends and family seem to understand more than my coworkers and employer do. Many people stress about losing their job, and when I feel as though people see me as less able with my hearing loss, it definitely worries me. I know I shouldn't worry as much as I do, but it is difficult to not think that way. My job is also very demanding and requires a lot of time spent communicating. On a daily basis, I have many different tasks, including checking people in for their appointments, scheduling appointments, clerical work for the department (typing up forms, handouts, educational materials, etc.), and advertising. I have also recently been asked to start taking minutes during the departmental meetings. My job requires a lot of communication skills, both verbal skills as well as listening skills. I communicate in person and over the telephone; however, I have difficulties when trying to hear people over the phone. When using the phone most people were understanding, and receptive, however, there has been the odd person that struggles to make changes to help me communicate with them better. Some people just become frustrated and give up trying.

My challenges at work are ongoing. My role as team assistant constantly changes. I need to be very attentive and need to understand what is being said over the telephone. The one other major problem I have at work is that I cannot understand the PA system. Coworkers, unfortunately, also don't realize that I am not hearing very well and will begin to whisper during conversations. They also don't realize that when they are having a conversation right next to my desk, that I am not involved in, it makes it very hard for me to not pick up those noises and to ignore them. It is very challenging and exhausting.

My boss realizes that I have workplace accommodations; however she is not doing what she should be doing. She has been reminded several times, by the employment consultant and my audiologist, but is not following their directions. I want to show her that I can continue to do my job, however she is not making that easy for me. An example that stands out in my mind is during a meeting when I was asked to take minutes, my boss who was leading the meeting continued the meeting without providing me any help or directions. When I asked to pause the meeting to catch up, I was told by my boss to not worry about it because she had a memory stick. That is not fair. The completed minutes state that she helped me transcribe them and then she went ahead and changed the minutes. Anytime I asked for help or accommodations, she did not acknowledge my request and continued on with what she was doing. She did not communicate well with me and she was not working with me to improve the communication between us. She always made me feel as though I was being a bother.

The constant learning at work is also very draining. Although I have been doing my job for several years and know it quite well, things are always changing and there is always new processes to learn. Trying to continuously learn new things while dealing with a hearing loss is exhausting.

Most of my coworkers treat me with respect. They are understanding and helpful. The employee health nurse at work and my audiologist are my 'go-tos'. They have always been able to do their best to help me. My coworkers try their best to follow instructions, however they do often forget, when they get excited to share ideas or start whispering to keep information secret. They are good about trying to change their habits when they are reminded. The one person I am really struggling with is my boss; I feel that we are reaching the point of harassment.

I am now at the point in my career where I have to decide within the next couple of weeks whether I want to go to human resources to discuss how I'm feeling.

Unfortunately, the last time I did say something to my boss, nothing happened so I went to her boss and we had a big meeting with human resources and the blame ended up coming back onto me. That was hard and I don't know if I want to go through that again.

I felt as though my voice was not being heard and that human resources was just taking my boss' side. I was the one who had called the meeting and the end outcome was that I ended up getting written up. I have never in 30 years had something like this happen. I am thankful for The Ontario Human Rights Code and the Accessibility for Ontarians with Disabilities Act. Every team member in the hospital was required to read a package of information that discussed accommodations for people with disabilities.

Before deciding to go to human resources, a meeting was held with my boss and other coworkers. My coworkers tried convincing me to call the meeting, but I was afraid to do so because I was afraid I could lose my job. Although I did not want to express my challenges and frustrations in this meeting, another coworker announced that I needed to share how I was feeling. I understood that there were things that needed to be said, however I think that after dealing with the stress and frustration for so long, you get in your own little shell and do what you can to stay in it. Fortunately, I quickly realized that I was not the only one feeling this way and that other employees were also experiencing difficulties with my boss. It was a great feeling to know that I was not alone and that this was not just a personal problem. This meeting gave my boss the opportunity to make changes on her behalf before some of us went to human resources. No changes were made, however within a month or two, my boss retired before I had the chance to go to human resources with my complaint. Team members and other coworkers, including myself were all very happy about this change.

The new coordinator, who is in charge right now until someone else is hired, has been amazing. She is very supportive and has informed me that I will be back in my original position and will have the support that I need in order to help me succeed. She understood that I have always had my place of employment in my best interest and that I have always done the best I can do at work. She assured me that everything was going to be fine. I feel much more comfortable talking to her and my other coworkers now. Once my boss finished, I informed everyone that I was on the list for cochlear implants and that I could receive a call at any time. I have a meeting with the employee health nurse next week to finalize some things. Everyone reacted in a very positive and supportive way which made me feel very good. I explained to my boss that I would make sure I kept her

informed as soon as I received any further information. Her only concern at this point is how things are going to look directly after the surgery because I do not have anyone that is able to cover my position. I suggested that I could continue coming to work, but limit the amount of communication tasks I am doing. I could use this time to complete some paper work that I never seem to have the time for. It was nice being able to give my input and have it accepted.

My friends and family are doing well. My outside of work life has definitely been affected, but my husband and I do our best to adapt. For example, when we go out to a restaurant, he will wear the wireless microphone that connects to my hearing aids and he is my back up in case I miss something. He explains to people that I have a hearing loss. My family as a whole has been very understanding. They always have lots of questions, but as soon as I find anything out, I tell them. I have sent them sample videos of what they might be doing for the cochlear implant surgery.

Outside of work, I do feel like most activities that I like to do require a lot more time and effort. I really enjoy swimming and I try to go as much as I can, but some days it just seems like too much work. I have to check the swim times, make sure there is somewhere safe to put my hearing aids and then speak to the life guard when I arrive to make sure they let me know if there is anything I need to hear. The need to identify myself everywhere I go is very exhausting. It would be great to have something like a bracelet that identifies me as a hard-of-hearing individual. I am fine with society and people I do not know. Society as a whole has been quite good to me. My main concern is when I have to disclose my hearing loss to someone I know. I am afraid of how they might feel towards me.

I also still go the movies and theatrical productions. The theatre was a downer because I could not hear anything the actors were saying; however I had great luck with the movies and will likely go back because the amplification was good. Anytime I find myself in a group, all activities become challenging because there is too much noise and too much going on for me to be able to use my wireless microphone. I find myself still attending



social activities, however they are becoming more challenging and I do find myself much more exhausted afterwards.

My audiologist referred me to the lip reading course at Western and an ear-nose-and-throat specialist in London. I have been seeing him for a long time however I haven't met the criteria for cochlear implants up until very recently when my hearing loss became so poor that cochlear implants could benefit me more than hearing aids. I did not tell my boss that I met this criteria right away because it is a long process and I know that she is not likely to be very supportive. The problem I face is that my right ear is the ear that gives me the most trouble, but they want to operate on my left ear which is the ear I rely on as it is more stable. This scares me. I know there is going to be a learning curve and I am nervous knowing that the hearing capabilities I currently have may be taken away from me. I am already at the point at work where things are starting to get bad and I don't want to have to start trying to cope in a new situation.

I have been told that it could be anywhere from three months to a year before I am called. Once I am called, the surgery takes place within a couple of weeks. If I do not feel prepared when I am called, I can ask to defer my date and they will call me back when they have availability. I understand the cochlear implant is a good thing; however it is scary and does make me nervous. It is going to be very different for me. There are many things that I constantly concern myself with. I worry about swimming and if this is still something that I will be able to do. I have to keep telling myself that I have made it this far, so I know I will be able to cope and I will face the challenges as they arise.

The agency that has services for persons with hearing loss was also able to help me with several resources at home. They set me up with everything I needed. I currently use the visual doorbell, the alarm clock bed shaker and visual fire alarms. I also have a separate wireless microphone for home. I have had great luck with all of the resources thus far. Everything has been great. I am up for learning more things; however it is difficult to find the time to get to the city during the week. I would appreciate additional information about coping strategies that is more accessible to where I live.

The one thing that I know I can improve on is bringing my situation forward in larger groups. I do find myself explaining my situation to more individuals, but not in group settings. I had one coworker come to me and ask me what my wireless microphone was. I explained what it was and that I have a hearing loss and she was very accepting and pleased to have learned that new information. I have not had the courage yet to bring my wireless microphone to the front during a full hospital meeting. I feel like my peers or people who do not know me well will start talking and whispering about me and that they will have the feeling that I cannot do my job. I was at a meeting recently when the CEO asked me a question and I had to ask the person beside me to repeat the question because I was too afraid to bring my wireless microphone to the front. I am getting better at coming out of my shell, but I know I still have improvements to make.

One of the positive outcomes is that I am functioning and I am making it through. It is extremely difficult, but my audiologist has told me that I am a prime patient to take to a conference to show other people that you can fight the struggles and succeed. I know that I cope and I don't cope depending on the day and the situation. I am able to tell people, especially friends and family about my hearing loss and I can address them when I did not hear something. I feel as though I have accessed many resources, all which have been very helpful and I am more than interested to learn about any other possibilities, in particular any tools or electronics that may be beneficial for me.

I want to do my best to get my story out to as many people as I can. I want people to understand that you can still communicate, work, and participate in social activities with a hearing loss. I know what it is like now when seniors ask for constant repetitions. I am still very young to have the degree of hearing loss that I have and I want to share both my struggles and my successes with as many people as possible. There are lots of people still working while experiencing hearing loss and I know that they likely have similar challenges to myself. I understand that it is a difficult disability to live with, but with determination and positivity, you can make the best of it.

## Appendix B: Office of Research Ethics Approval Notice



Research Ethics

### Western University Health Science Research Ethics Board HSREB Delegated Initial Approval Notice

Principal Investigator: Dr. Marybeth Jennings  
Department & Institution: Health Sciences/Communication Sciences & Disorders, Western University

Review Type: Delegated  
HSREB File Number: 107972  
Study Title: Accessing resources- the narratives of women working with a hearing loss.

HSREB Initial Approval Date: June 07, 2016  
HSREB Expiry Date: June 07, 2017

#### Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Recruitment Items	Appendix F- Advertisement	2016/05/09
Other	Appendix E- Authorization to Obtain Personal Health Record	2016/05/09
Other	Appendix C- Resources Available for Participants	2016/05/09
Other	Appendix D- AR Groups Flyer	2016/05/09
Other	Appendix B- Interview Guidelines	2016/05/09
Other	Appendix A- Data Collection Form	2016/05/09
Letter of Information & Consent	Appendix G- Letter of Information	2016/05/09
Western University Protocol		2016/05/09

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer: Erika Basile \_\_\_ Nicole Kasiki \_\_\_ Grace Kelly \_\_\_ Katelyn Harris \_\_\_ Nikki Trud \_\_\_ Karen Gopal \_\_\_

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